# Major Birth Defects Data from Population-based Birth Defects Surveillance Programs in the United States, 2006-2010

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Prepared by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

This report contains data from 41 population-based birth defects programs. These include: Alaska Birth Defects Registry; Arizona Birth Defects Monitoring Program; Arkansas Reproductive Health Monitoring System; California Birth Defects Monitoring Program; Colorado Responds To Children With Special Needs; Delaware Birth Defects Surveillance Project; Florida Birth Defects Registry; Metropolitan Atlanta Congenital Defects Program (Georgia); Illinois Adverse Pregnancy Outcomes Reporting System; Indiana Birth Defects & Problems Registry; Iowa Registry For Congenital and Inherited Disorders; Kansas Birth Defects Information System; Kentucky Birth Surveillance Registry; Louisiana Birth Defects Monitoring Network; Maine Birth Defects Program; Maryland Birth Defects Reporting and Information System; Massachusetts Center For Birth Defects Research And Prevention; Michigan Birth Defects Registry; Minnesota Birth Defects Information System; Mississippi Birth Defects Registry; Nebraska Birth Defects Registry; Nevada Birth Outcomes Monitoring System; New Hampshire Birth Conditions Program; New Jersey Special Child Health Services Registry; New York State Congenital Malformations Registry; North Carolina Birth Defects Monitoring Program; North Dakota Birth Defects Monitoring System; Ohio Connections For Children With Special Needs; Oklahoma Birth Defects Registry; Puerto Rico Birth Defects Surveillance and Prevention System; Rhode Island Birth Defects Program; South Carolina Birth Defects Program; Tennessee Birth Defects Registry; Texas Birth Defects Epidemiology and Surveillance Branch; Utah Birth Defect Network; Vermont Birth Information Network; Virginia Congenital Anomalies Reporting And Education System; Washington State Birth Defects Surveillance System; West Virginia Congenital Abnormalities Registry, Education and Surveillance System; Wisconsin Birth Defects Registry; and the United States Department of Defense Birth and Infant Health Registry.

Additional information and program contacts on population-based birth defects surveillance programs are available on page S122.

Alaska Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal R	ace/Ethnicity			
Defect	Non- Hispanic White	American Indian or Alaska Native	Total**	Notes
Anencephalus	<6	<6	11	
Anophthalmia/microphthalmia	· <6	· <6	<b>2.0</b> 11	
Anotia/microtia	. 10	. 11	<b>2.0</b> 22	
Aortic valve stenosis	<b>2.9</b> 6	<b>7.9</b> 0	<b>3.9</b> 6	
	1.8	0.0	1.1	
Atrial septal defect	434 127.8	133 <b>95.1</b>	878 <b>157.4</b>	
Atrioventricular septal defect (endocardial cushion defect)	18 <b>5.3</b>	11 7.9	34 <b>6.1</b>	
Biliary atresia	<6	14	18	
Choanal atresia	8	<b>10.0</b> <6	<b>3.2</b> 15	
Cleft lip with and without cleft palate	<b>2.4</b> 46	53	2.7 112	
	13.5 30	<b>37.9</b> 63	<b>20.1</b> 99	
Cleft palate without cleft lip	8.8	45.1	17.7	
Coarctation of aorta	20 <b>5.9</b>	8 <b>5.</b> 7	30 <b>5.4</b>	
Common truncus	<6	<6	10 <b>1.8</b>	
Congenital cataract	11	17	32	
Congenital hip dislocation	<b>3.2</b> 74	<b>12.2</b> 28	<b>5.7</b> 114	
Diaphragmatic hernia	<b>21.8</b> 12	<b>20.0</b> 18	<b>20.4</b> 32	
	3.5	12.9	<b>5.</b> 7	
Down syndrome (Trisomy 21)	44 <b>13.0</b>	28 <b>20.0</b>	87 <b>15.6</b>	
Ebstein anomaly	<6	<6	8 1.4	
Encephalocele	10 <b>2.9</b>	11 7.9	23 4.1	
Epispadias	8	<6	10	
Esophageal atresia/tracheoesophageal fistula	<b>2.4</b> 6	7	<b>1.8</b> 15	
Hirschsprung disease (congenital megacolon)	1.8 20	<b>5.0</b> 16	2.7 41	
	5.9	11.4	7.3	
Hydrocephalus without spina bifida	24 7.1	17 12.2	55 <b>9.9</b>	
Hypoplastic left heart syndrome	10 <b>2.9</b>	<6	15 <b>2.</b> 7	
Hypospadias*	209	47	304	
Microcephalus	118.9 52	65.2 44	105.5 106	
Obstructive genitourinary defect	<b>15.3</b> 197	<b>31.5</b> 84	<b>19.0</b> 321	
Patent ductus arteriosus	<b>58.0</b> 265	<b>60.1</b> 170	<b>57.5</b> 512	1
	78.0	121.6	91.8	1
Pulmonary valve atresia and stenosis	36 <b>10.6</b>	40 <b>28.6</b>	84 <b>15.1</b>	
Pyloric stenosis	74 21.8	63 <b>45.1</b>	144 <b>25.8</b>	
Rectal and large intestinal atresia/stenosis	32	22	58	
Reduction deformity, lower limbs	<b>9.4</b> 26	15.7 16	10.4 48	
Reduction deformity, upper limbs	7.7 12	<b>11.4</b> 10	<b>8.6</b> 27	
reduction deformity, upper minos	3.5	7.2	4.8	

Alaska Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal	Maternal Race/Ethnicity								
Defect	Non- Hispanic White	American Indian or Alaska Native	Total**	Notes					
Renal agenesis/hypoplasia	24 7.1	11 7.9	42 7.5						
Spina bifida without anencephalus	18 <b>5.3</b>	12 <b>8.6</b>	31 <b>5.6</b>						
Tetralogy of Fallot	13 <b>3.8</b>	15 <b>10.7</b>	31 <b>5.6</b>						
Total anomalous pulmonary venous return (TAPVR)	<6	6 <b>4.3</b>	12 2.2						
Transposition of great arteries - All	13 <b>3.8</b>	12 <b>8.6</b>	26 <b>4.</b> 7						
Tricuspid valve atresia and stenosis	<6	<6	6 1.1						
Trisomy 13	<6	<6	7 <b>1.3</b>						
Trisomy 18	<6	<6	10 <b>1.8</b>						
Ventricular septal defect	252 <b>74.2</b>	256 183.1	553 <b>99.1</b>	2					
Total Live Births	33969	13983	55785						
Total Male Live Births	17572	7208	28802						

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Alaska Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age								
Defect	Less than 35	35 and greater	Total**	Notes				
Down syndrome (Trisomy 21)	49 <b>10.0</b>	38 <b>56.1</b>	87 <b>15.6</b>					
Trisomy 13	5 <b>1.0</b>	2 <b>3.0</b>	7 1.3					
Trisomy 18	4 <b>0.8</b>	6 <b>8.9</b>	10 <b>1.8</b>					
Total Live Births	441090	60975	502065					

<sup>\*\*</sup>Total includes unknown maternal age

- 1.Patent ductus arteriosus only includes those with birth weight greater or equal to 2500 grams
- 2. Ventricular septal defect The ABDR is a passive surveillance system. Reports are not submitted as 'probable'. However, the ABDR does not conduct case verification on these reports.

- -Alaska conducts surveillance for FAS using FASSNET methodology. Contact the program for data on FAS and FASD.
- -Cases matched to Alaska birth certificates only; birth cohort 2002-2006 for major anomalies only (see attached lists of ICD9 codes).
- -Data was indicated by race for non-Hispanic White and non-Hispanic AK Native only. Live birth numbers were queried from VS data sets and not from published VS data as VS does not publish breakdowns on these two races with indicated ethnicity.
- -Gastroschisis and omphalocele are not separated and are reported under the same ICD9 code.
- -The ABDR does not collect data on still births or terminations; live birth information only.
- -The ABDR does not collect or provide information on amniotic bands.
- -The ABDR does not provide data to any other state agency for the purpose of further metabolic and/or medical testing.
- -The ABDR does not provide numbers for cells with <6 cases.
- -The Alaska Birth Defects Registry does not provide data on individual years within the birth cohort; only totals by race and age are presented with individual year data.
- -The Alaska Birth Defects Registry uses the ICD-9 coding system.

Arizona Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity									
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes			
Anencephalus	19	3	45	1	3	72				
Aniridia	<b>0.9</b> 2	1.5 0	2.2	<b>0.6</b> 1	<b>1.0</b> 0	1.5 5				
	0.1	0.0	0.1	0.6	0.0	0.1				
Anophthalmia/microphthalmia	10 <b>0.5</b>	1 <b>0.5</b>	24 1.2	1 <b>0.6</b>	3 1.0	40 <b>0.8</b>				
Anotia/microtia	14	0	33	3	7	57	1			
A 1: 1 1 1:	0.7	0.0	1.6	1.9	2.3	1.2				
Aortic valve stenosis	34 1.7	4 2.1	46 2.2	2 1.3	4 1.3	90 <b>1.9</b>				
Atrioventricular septal defect	2	0	0	0	0	2				
(endocardial cushion defect)	<i>0.1</i> 4	<b>0.0</b> 2	<b>0.0</b> 5	<b>0.0</b> 2	<b>0.0</b> 2	<b>0.0</b> 15				
Biliary atresia	0.2	1.0	0.2	1.3	0.7	<b>0.3</b>				
Bladder exstrophy	2	0	5	0	0	7				
Choanal atresia	<b>0.1</b> 20	<b>0.0</b>	<b>0.2</b> 16	<b>0.0</b> 0	<b>0.0</b>	<b>0.1</b> 40				
Choanar atresia	1.0	0.5	0.8	0.0	0.3	0.8				
Cleft lip with and without cleft palate	185	14	234	12	61	514				
Cleft palate without cleft lip	<b>9.1</b> 118	<b>7.2</b> 7	11.3 134	<b>7.6</b> 14	<b>20.0</b> 19	10.6 298				
	5.8	3.6	6.5	8.9	6.2	6.2				
Coarctation of aorta	104	6	81	6	13	212				
Common truncus	<b>5.1</b> 8	3.1 2	3.9 10	3.8 1	<b>4.3</b>	4.4 23				
	0.4	1.0	0.5	0.6	0.3	0.5				
Congenital cataract	7 <b>0.3</b>	0 <b>0.0</b>	17 <b>0.8</b>	0 <b>0.0</b>	3 1.0	29 <b>0.6</b>				
Diaphragmatic hernia	37	3	44	2	8	97				
	1.8	1.5	2.1	1.3	2.6	2.0				
Down syndrome (Trisomy 21)	239 11.7	19 <b>9.8</b>	253 <b>12.2</b>	16 <b>10.2</b>	35 11.5	571 <b>11.8</b>				
Ebstein anomaly	13	0	15	2	5	36				
	0.6	0.0	0.7	1.3	1.6	0.7				
Encephalocele	9 <b>0.4</b>	1 <b>0.5</b>	16 <b>0.8</b>	2 1.3	4 1.3	32 <b>0.</b> 7				
Esophageal atresia/tracheoesophageal	51	3	43	1	4	102				
fistula	2.5	1.5	2.1	0.6	1.3	2.1				
Gastroschisis	93 <b>4.6</b>	6 <b>3.1</b>	97 <b>4.</b> 7	7 <b>4.5</b>	24 7.9	235 <b>4.9</b>				
Hirschsprung disease (congenital	28	3	26	2	0	61				
megacolon)	<b>1.4</b> 59	<b>1.5</b> 8	<b>1.3</b> 47	1.3 4	0.0	1.3 132				
Hypoplastic left heart syndrome	2.9	o 4.1	2.3	2.5	12 <b>3.9</b>	2.7				
Omphalocele	34	3	37	7	4	87				
Pulmonary valve atresia and stenosis	1.7 86	<b>1.5</b> 5	1.8 100	<b>4.5</b> 8	1.3 18	<b>1.8</b> 221				
1 unionary varve aresia and stenosis	4.2	2.6	4.8	<b>5.1</b>	5.9	4.6				
Pulmonary valve atresia	39	3	42	4	6	97				
Reduction deformity, lower limbs	<b>1.9</b> 10	<b>1.5</b> 6	<b>2.0</b> 23	<b>2.5</b>	2.0	<b>2.0</b> 43				
· · · · · · · · · · · · · · · · · · ·	0.5	3.1	1.1	0.6	0.7	0.9				
Reduction deformity, upper limbs	36	7	49	2	9	107				
Spina bifida without anencephalus	<b>1.8</b> 62	<b>3.6</b> 7	<b>2.4</b> 79	<b>1.3</b> 3	<b>3.0</b> 16	<b>2.2</b> 173				
	3.0	3.6	3.8	1.9	5.3	3.6				
Tetralogy of Fallot	86	5	82	5	17	199				
Total anomalous pulmonary venous return	4.2	<b>2.6</b> 0	<b>4.0</b>	<b>3.2</b> 0	<b>5.6</b> 2	<b>4.1</b> 11				
(TAPVR)	1.3	0.0	1.2	0.0	3.5	1.3				
Transposition of great arteries - All	49	5	53	5	5	120				
dextro-Transposition of great arteries	<b>2.4</b> 48	<b>2.6</b> 5	<b>2.6</b> 42	3.2 4	<b>1.6</b> 4	<b>2.5</b> 106				
(d-TGA)	2.4	2.6	2.0	2.5	1.3	2.2				

Arizona Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity										
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes				
Tricuspid valve atresia and stenosis	2 <b>0.5</b>	0 <b>0.0</b>	2 <b>0.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 0.5					
Tricuspid valve atresia	2 <b>0.5</b>	0 <b>0.0</b>	2 <b>0.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 0.5					
Trisomy 13	16 <b>0.8</b>	4 2.1	24 1.2	7 <b>4.</b> 5	2 <b>0.</b> 7	53 1.1					
Trisomy 18	36 <b>1.8</b>	3 1.5	35 1.7	5 <b>3.2</b>	10 <b>3.3</b>	89 <b>1.8</b>					
Ventricular septal defect	7 <b>1.6</b>	0 <b>0.0</b>	11 <b>2.4</b>	0 <b>0.0</b>	5 <b>8.1</b>	23 2.3					
<b>Total Live Births</b>	203663	19366	207183	15693	30448	482974					

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Arizona Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age								
Defect	Less than 35	35 and greater	Total**	Notes				
Down syndrome (Trisomy 21)	313	258	571					
	7.4	41.5	11.8					
Trisomy 13	37	16	53					
	0.9	2.6	1.1					
Trisomy 18	58	30	89					
•	1.4	4.8	1.8					
<b>Total Live Births</b>	420596	62242	482974					

<sup>\*\*</sup>Total includes unknown maternal age

1.Only reportable if occurring with confirmed hearing loss.

- -ABDMP provides data on 30 categories of birth defects through 2009, and 32 categories beginning in 2010.
  -ABDMP tables include only confirmed cases with 'most likely,' 'probable,' or 'precise' diagnoses. 'Possible' diagnoses are not included.
  -In this data submission, ABDMP adhered to the requested race/Hispanic categories. However, for traditional in-state reports ABDMP categorizes Whites as Hispanic or non-Hispanic, and for other races (i.e. Black, Asian, and American Indian) retains the single race code regardless of their Hispanic
- -Registration of liveborn cases by ABDMP requires an Arizona live birth certificate.
- -Stillbirths are included in this report if there is an Arizona fetal death certificate, regardless of fetal weight or gestational age.
- -Terminations are not included in ABDMP data reports.

Arkansas Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Amniotic bands	27	11	3	1	0	42	
Anencephalus	<b>2.0</b> 47	<b>2.8</b> 6	1.4 13	<b>2.3</b> 0	<b>0.0</b>	<b>2.1</b> 66	
	3.5	1.6	6.1	0.0	0.0	3.3	
Aniridia	3 <b>0.2</b>	1 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 <b>0.2</b>	
Anophthalmia/microphthalmia	24	4	3	0.0	1	32	
• •	1.8	1.0	1.4	0.0	9.2	1.6	
Anotia/microtia	22 <b>1.6</b>	2 <b>0.5</b>	19 <b>8.9</b>	1 2.3	0 <b>0.0</b>	44 2.2	
Aortic valve stenosis	59	5	6	0	0	70	
4	4.4	1.3	2.8	0.0	0.0	3.5	
Atrial septal defect	423 <b>31.4</b>	102 <b>26.4</b>	59 <b>27.</b> 7	19 <b>43.</b> 7	5 <b>46.1</b>	608 <b>30.4</b>	
Atrioventricular septal defect	100	27	10	4	0	141	
(endocardial cushion defect)	7.4	7.0	4.7	9.2	0.0	7.0	
Biliary atresia	4 <b>0.3</b>	2 <b>0.5</b>	0 <b>0.0</b>	1 2.3	0 <b>0.0</b>	7 <b>0.3</b>	
Bladder exstrophy	4	1	0	0	0	5	
Characteris	0.3	0.3	0.0	0.0	0.0	0.2	
Choanal atresia	7 <b>0.5</b>	4 1.0	0 <b>0.0</b>	0 <b>0.0</b>	9.2	12 <b>0.6</b>	
Cleft lip with and without cleft palate	168	31	16	2	0	217	
Claft polata without alaft lin	12.5 106	<b>8.0</b> 23	7.5 11	4.6	0.0	10.8 141	
Cleft palate without cleft lip	7.9	5.9	5.2	0 <b>0.0</b>	9.2	7.0	
Coarctation of aorta	113	20	12	0	0	145	
Common transport	<b>8.4</b> 9	<b>5.2</b> 3	<b>5.6</b> 2	<b>0.0</b> 1	0.0	7.2 15	
Common truncus	<b>0.</b> 7	0.8	0.9	2.3	0.0	0.7	
Congenital cataract	53	13	7	1	1	75	
Congenital hip dislocation	<b>3.9</b> 17	<i>3.4</i> 3	<b>3.3</b> 3	<b>2.3</b>	<b>9.2</b> 0	3.7 24	
Congenital inp dislocation	1.3	0.8	1.4	2.3	0.0	1.2	
Diaphragmatic hernia	48	9	5	0	0	62	
Down syndrome (Trisomy 21)	<b>3.6</b> 176	2.3 26	<b>2.3</b> 33	<b>0.0</b> 3	0.0	3.1 238	
Down syndrome (Trisomy 21)	13.1	<b>6.</b> 7	15.5	6.9	0.0	11.9	
Ebstein anomaly	11	2	4	0	1	18	
Encephalocele	<b>0.8</b> 14	<i>0.5</i>	1.9 4	<b>0.0</b> 0	9.2	<b>0.9</b> 29	
Encephalocele	1.0	2.8	1.9	0.0	0.0	1.4	
Epispadias	9	1	0	0	0	10	
Esophageal atresia/tracheoesophageal	<b>0.</b> 7 48	<b>0.3</b> 8	<b>0.0</b> 3	<b>0.0</b> 2	0.0	<b>0.5</b> 61	
fistula	3.6	2.1	1.4	4.6	0.0	3.0	
Gastroschisis	95 7.1	19	9	1	2	126	
Hirschsprung disease (congenital	7.1 40	<b>4.9</b>	<b>4.2</b> 2	<b>2.3</b>	18.5 0	<b>6.3</b> 54	
megacolon)	3.0	2.8	0.9	2.3	0.0	2.7	
Hydrocephalus without spina bifida	71 <b>5.3</b>	23 <b>5.9</b>	14 <b>6.6</b>	2 <b>4.6</b>	0 <b>0.0</b>	110 <b>5.5</b>	
Hypoplastic left heart syndrome	59	13	1	1	1	75	
	4.4	3.4	0.5	2.3	9.2	<i>3.7</i>	
Hypospadias*	622 <b>89.6</b>	131 <b>66.9</b>	27 <b>25.1</b>	10 <b>45.0</b>	7 <b>129.2</b>	797 <i>77.7</i>	
Microcephalus	25	10	6	3	1	45	
	1.9	2.6	2.8	6.9	9.2	2.2	
Obstructive genitourinary defect	220 <b>16.4</b>	55 <b>14.2</b>	35 <b>16.4</b>	5 <b>11.5</b>	2 18.5	317 <b>15.8</b>	
Omphalocele	27	18	3	0	0	48	
	2.0	4.7	1.4	0.0	0.0	2.4	
Patent ductus arteriosus	112 <b>8.3</b>	32 <b>8.3</b>	20 <b>9.4</b>	5 <b>11.5</b>	3 <b>27.</b> 7	172 <b>8.6</b>	1

Arkansas Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity									
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes			
Pulmonary valve atresia and stenosis	184	54	27	9	2	276				
	13.7	14.0	12.7	20.7	18.5	13.8				
Pulmonary valve atresia	8	4	3	1	0	16				
	0.6	1.0	1.4	2.3	0.0	0.8				
Pyloric stenosis	283	31	59	3	3	379				
	21.0	8.0	27.7	6.9	27.7	18.9				
Rectal and large intestinal atresia/stenosis		27	20	5	1	146				
	6.9	7.0	9.4	11.5	9.2	7.3				
Reduction deformity, lower limbs	32	17	4	0 <b>0.0</b>	0 <b>0.0</b>	53				
Dadastian dafamaita aman limba	2.4	4.4	<b>1.9</b> 12			<b>2.6</b> 98				
Reduction deformity, upper limbs	69 <b>5.1</b>	11 <b>2.8</b>	5.6	6 <b>13.8</b>	0 <b>0.0</b>	98 <b>4.9</b>				
D1	28	13	9			50				
Renal agenesis/hypoplasia	2.1 2.1	3.4	4.2	0 <b>0.0</b>	0 <b>0.0</b>	2.5				
Spina bifida without anencephalus	68	7	12	1	0.0	88				
Spina offica without anencephatus	5.1	1.8	5.6	2.3	0.0	4.4				
Tetralogy of Fallot	63	14	6	2.3	0.0	85				
Tetralogy of Fallot	<b>4.</b> 7	3.6	2.8	4.6	0.0	4.2				
Total anomalous pulmonary venous return		5	2.0	2	1	26				
(TAPVR)	1.2	1.3	0.9	4.6	9.2	1.3				
Transposition of great arteries - All	64	13	5	2	0	84				
Transposition of great arteries Tim	4.8	3.4	2.3	4.6	0.0	4.2				
dextro-Transposition of great arteries	55	11	4	2	0	72				
(d-TGA)	4.1	2.8	1.9	4.6	0.0	3.6				
Tricuspid valve atresia and stenosis	6	2	4	1	0	13				
<b>F</b>	0.4	0.5	1.9	2.3	0.0	0.6				
Tricuspid valve atresia	6	2	4	1	0	13				
•	0.4	0.5	1.9	2.3	0.0	0.6				
Trisomy 13	16	4	2	0	0	22				
	1.2	1.0	0.9	0.0	0.0	1.1				
Trisomy 18	38	11	6	0	0	55				
	2.8	2.8	2.8	0.0	0.0	2.7				
Ventricular septal defect	839	151	163	28	5	1186				
	62.4	39.1	76.4	64.5	46.1	59.3				
<b>Total Live Births</b>	134507	38661	21325	4344	1084	200066				
<b>Total Male Live Births</b>	69383	19584	10753	2222	542	102552				

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

**Arkansas** 

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age								
Defect	Less than 35	35 and greater	Total**	Notes				
Down syndrome (Trisomy 21)	147 <b>8.0</b>	91 <b>58.2</b>	238 11.9					
Trisomy 13	19 <b>1.0</b>	3 1.9	22 <b>1.1</b>					
Trisomy 18	30 <b>1.6</b>	25 <b>16.0</b>	55 <b>2.</b> 7					
<b>Total Live Births</b>	184406	15636	200066					

<sup>\*\*</sup>Total includes unknown maternal age

# Notes

1.The case definition for patent ductus arteriosus changed starting with 2009 births.

- -A locally modified 6-digit BPA/CDC coding system is used for coding birth defects. -Livebirth data for 2010 births are provisional.

California Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

American Asian or Pacific Indian or		
White Black Islander Alaska Nati Defect Non-Hispanic Non-Hispanic Hispanic Non-Hispanic Non-Hispanic		Notes
Amniotic bands 10 <5 19 <5 <5 1.1 . 0.9	36 1.0	
Anencephalus 13 <5 61 <5 0	99	
1.5       .       2.9       .       0.0         Anophthalmia/microphthalmia       7       <5	2.9 24	
0.8 . 0.6 . 0.0	0.7	
Anotia/microtia 5 <5 73 8 <5 0.6 . 3.5 4.9 .	95 <b>2.8</b>	
Aortic valve stenosis 11 <5 23 <5 0 1.2 . 1.1 . 0.0	38 1.1	
Atrial septal defect 124 28 333 24 <5	528	1
14.0     17.7     15.9     14.8     .       Atrioventricular septal defect (endocardial 39     14     86     6     <5	15.3 152	
cushion defect) 4.4 8.9 4.1 3.7 .	4.4	
Biliary atresia 7 <5 9 <5 <5 0.8 . 0.4	21 <b>0.6</b>	
Bladder exstrophy <5 <5 <5 0	6	
	<b>0.2</b> 8	
. 0.0 0.2 0.0 0.0	0.2	
Cleft lip with and without cleft palate 75 <5 204 20 <5 <b>8.5</b> . <b>9.8</b> 12.3 .	325 <b>9.4</b>	
Cleft palate without cleft lip 30 <5 92 <5 <5 3.4 . 4.4	141 <b>4.1</b>	2
Coarctation of aorta 44 6 81 <5 <5	147	
5.0     3.8     3.9     .     .       Common truncus     <5	<b>4.3</b> 8	
. 0.3 0.0 0.0	0.2	
Congenital cataract 10 <5 20 <5 0 1.1 . 1.0 . 0.0	35 <b>1.0</b>	
Diaphragmatic hernia 22 <5 51 5 <5 2.5 . 2.4 3.1 .	83 <b>2.4</b>	
Down syndrome (Trisomy 21) 98 20 318 <5 <5	487	
11.1 12.7 15.2 Ebstein anomaly 8 0 12 <5 0	14.1 23	
0.9 0.0 0.6 . 0.0	0.7	
Encephalocele <5 <5 16 <5 <5	27 <b>0.8</b>	
Esophageal atresia/tracheoesophageal 18 0 27 <5 <5 fistula 2.0 0.0 1.3 .	50 <b>1.5</b>	3
Fetus or newborn affected by maternal <5 0 <5 0	<5	
alcohol use       .       0.0       .       0.0       0.0         Gastroschisis       47       7       109       12       0	187	
5.3 4.4 5.2 7.4 0.0	5.4	
Hydrocephalus without spina bifida 18 <5 42 <5 <5 2.0	72 <b>2.1</b>	
Hypoplastic left heart syndrome 19 <5 34 5 0	66	
2.1 . 1.6 3.1 0.0 Hypospadias* 71 8 80 <5 <5	1.9 173	4
15.6     10.0     7.5     .       Omphalocele     7     <5	<b>9.8</b> 36	
0.8 . $1.0$ . $0.0$	1.0	
Pulmonary valve atresia and stenosis 57 9 117 15 <5 6.4 5.7 5.6 9.2 .	208 <b>6.0</b>	
Pulmonary valve atresia 10 <5 30 <5 <5	45	
Rectal and large intestinal atresia/stenosis 28 <5 75 11 <5	1.3 131	5
3.2 . 3.6 6.8 .  Reduction deformity, lower limbs 12 <5 15 0 <5	<b>3.8</b> 30	
1.4 . 0.7 0.0 .	0.9	
Reduction deformity, upper limbs 21 5 52 5 <5 2.4 3.2 2.5 3.1 .	89 <b>2.6</b>	
Renal agenesis/hypoplasia 6 0 20 <5 0 0 0.7 0.0 1.0 . 0.0	31 <b>0.9</b>	6

California Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Spina bifida without anencephalus	33 3.7	<5 •	83 <b>4.0</b>	<5 •	<5 •	141 <b>4.1</b>	
Tetralogy of Fallot	29 <b>3.3</b>	<5 •	61 <b>2.9</b>	5 <b>3.1</b>	0 <b>0.0</b>	97 <b>2.8</b>	
Total anomalous pulmonary venous return (TAPVR)	1. <b>0</b>	0 <b>0.0</b>	34 <b>1.6</b>	<5 •	<5 •	46 1.3	
Transposition of great arteries - All	16 <b>1.8</b>	<5 •	29 <b>1.4</b>	<5 •	0 <b>0.0</b>	50 <b>1.5</b>	
dextro-Transposition of great arteries (d-TGA)	16 <b>1.8</b>	<5 •	29 <b>1.4</b>	<5 •	0 <b>0.0</b>	50 <b>1.5</b>	
Tricuspid valve atresia	6 <b>0.</b> 7	0 <b>0.0</b>	13 <b>0.6</b>	<5 •	0 <b>0.0</b>	20 <b>0.6</b>	
Trisomy 13	9 <b>1.0</b>	<5 •	19 <b>0.9</b>	<5 •	0 <b>0.0</b>	39 <b>1.1</b>	
Trisomy 18	20 2.3	<5 •	57 <b>2.</b> 7	<5 •	0 <b>0.0</b>	107 <b>3.1</b>	
<b>Total Live Births</b>	88656	15778	209068	16240	2667	344413	
<b>Total Male Live Births</b>	45651	8005	106240	8322	1371	175758	

<sup>&</sup>lt;5 indicates cell size suppressed to protect confidentiality and/or to indicate case count less than 5. \*Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

# California

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)								
Defect	Less than 35	35+	Total**	Notes				
Down syndrome (Trisomy 21)	249	226	487					
	8.1	58.9	14.1					
Trisomy 13	23	11	39					
•	0.8	2.9	1.1					
Trisomy 18	50	40	107					
	1.6	10.4	3.1					
Total Live Births	305987	38366	344413					

<sup>\*\*</sup>Total includes unknown maternal age

### Notes

- 1.Atrial septal defect (ASD) cases are included if confirmed by physician review or echo or cath or surgery or autopsy; an ASD that is a component of another major heart malformation is not counted.
- 2. Submucous cleft and bifid uvula are not included in this report.
- 3.Isolated tracheoesophageal fistula is not included in this report.
- 4. Hypospadias case counts include only 2nd and 3rd degree.
- 5. Anal stenosis is not included in this report.
- 6.Unilateral renal agenesis/hypoplasia is not included in this report.

- -Cases with chromosomal defects other than trisomy 13, 18 and 21 are not included in this report.
- -Cases with single gene disorders are not included in this report.
- -Stillbirth greater than or equal to 20 weeks is included for all defect types.
  -The criteria used to identify birth defects case counts have been refined from that used in previous years to reflect variations in data collection ascertainment rules for certain birth defects in some counties and birth years.

Colorado Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Anencephalus	26 1.3	2 1.3	23 <b>2.1</b>	2 1.7	1 <b>4.0</b>	58 <b>1.</b> 7	1
Aniridia	7	0	2	0	0	9	
Anophthalmia/microphthalmia	<b>0.3</b> 28	<b>0.0</b> 3	<b>0.2</b> 21	<b>0.0</b> 0	0.0	<b>0.3</b> 56	
•	1.4	1.9	1.9	0.0	0.0	1.6	
Anotia/microtia	45 <b>2.2</b>	6 <b>3.9</b>	46 <b>4.3</b>	3 <b>2.6</b>	1 <b>4.0</b>	105 <b>3.0</b>	
Aortic valve stenosis	75 <b>3.6</b>	4 2.6	33 <b>3.1</b>	0 <b>0.0</b>	1 <b>4.0</b>	115 <b>3.3</b>	
Atrial septal defect	2083	229	1171	128	25	3692	
Atrioventricular septal defect	101.1 84	147.9 12	108.6 38	<b>109.6</b> 5	100.6	106.5 144	2
(endocardial cushion defect)	4.1	7.8	3.5	4.3	8.0	4.2	
Biliary atresia	26 1.3	2 1.3	10 <b>0.9</b>	0 <b>0.0</b>	0 <b>0.0</b>	39 <b>1.1</b>	
Bladder exstrophy	7	0	3 <b>0.3</b>	0 <b>0.0</b>	1	11	
Choanal atresia	<b>0.3</b> 39	<b>0.0</b> 6	<b>0.3</b> 19	1	<b>4.0</b>	<b>0.3</b> 70	
Cleft lip with and without cleft palate	1.9 226	<b>3.9</b> 11	1.8 148	<b>0.9</b> 7	<b>4.0</b> 3	<b>2.0</b> 407	
	11.0	7.1	13.7	6.0	12.1	11.7	
Cleft palate without cleft lip	177 <b>8.6</b>	11 <b>7.1</b>	84 7 <b>.8</b>	4 <b>3.</b> 4	1 <b>4.0</b>	283 <b>8.2</b>	
Coarctation of aorta	193	13	98	3	1	312	
Common truncus	<b>9.4</b> 14	<b>8.4</b>	<b>9.1</b> 11	<b>2.6</b> 0	<b>4.0</b>	<b>9.0</b> 29	
C	0.7	<b>0.6</b> 2	1.0 24	0.0	<b>4.0</b> 0	0.8	
Congenital cataract	35 1.7	1.3	2.2	1 <b>0.9</b>	0.0	63 <b>1.8</b>	
Congenital hip dislocation	292 <b>14.2</b>	9 <b>5.8</b>	147 <b>13.6</b>	14 <b>12.0</b>	2 <b>8.0</b>	471 <b>13.6</b>	
Diaphragmatic hernia	74	7	31	4	0	124	
Down syndrome (Trisomy 21)	<b>3.6</b> 295	<b>4.5</b> 30	<b>2.9</b> 169	<b>3.4</b> 17	<b>0.0</b>	<b>3.6</b> 715	
	14.3	19.4	15.7	14.6	4.0	20.6	
Ebstein anomaly	20 1.0	0 <b>0.0</b>	7 <b>0.6</b>	3 <b>2.6</b>	0 <b>0.0</b>	30 <b>0.9</b>	
Encephalocele	15 <b>0. 7</b>	4 <b>2.6</b>	14 <b>1.3</b>	1 <b>0.9</b>	0 <b>0.0</b>	38 1.1	
Epispadias	21	3	9	0	0	33	
Esophageal atresia/tracheoesophageal	<b>1.0</b> 86	<b>1.9</b> 6	<b>0.8</b> 31	<b>0.0</b> 2	<b>0.0</b>	<b>1.0</b> 129	
fistula	4.2	3.9	2.9	1.7	4.0	3.7	
Gastroschisis	72 <b>3.5</b>	5 <b>3.2</b>	68 <b>6.3</b>	2 1.7	1 <b>4.0</b>	154 <b>4.4</b>	3
Hirschsprung disease (congenital	51	4	20	1	0	77	
megacolon) Hydrocephalus without spina bifida	2.5 134	<b>2.6</b> 20	1.9 108	<b>0.9</b> 7	<b>0.0</b> 3	2.2 279	
Hypoplastic left heart syndrome	<b>6.5</b> 51	<b>12.9</b> 5	<b>10.0</b> 30	<b>6.0</b> 0	<b>12.1</b> 0	<b>8.1</b> 88	
	2.5	3.2	2.8	0.0	0.0	2.5	
Hypospadias*	1492 <b>140.9</b>	108 <b>136.4</b>	391 <b>70.6</b>	52 <b>88.1</b>	15 <b>119.5</b>	2083 117.2	
Microcephalus	155	20	123	4	4	312	
Obstructive genitourinary defect	<b>7.5</b> 834	12.9 65	11.4 438	<b>3.4</b> 53	<b>16.1</b> 9	<b>9.0</b> 1426	
	40.5	42.0	40.6	45.4	36.2	41.2	
Omphalocele	38 <b>1.8</b>	5 3.2	21 <b>1.9</b>	1 <b>0.9</b>	0 <b>0.0</b>	77 2.2	4
Patent ductus arteriosus	849	94	460	47	11	1476	5
Pulmonary valve atresia and stenosis	<b>41.2</b> 147	<b>60.7</b> 16	<b>42.7</b> 95	<b>40.3</b> 8	<b>44.2</b> 1	<b>42.6</b> 270	
	7.1	10.3	8.8	6.9	4.0	7.8	

Colorado Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Pulmonary valve atresia	33	7	27	3	0	72		
	1.6	4.5	2.5	2.6	0.0	2.1		
Pyloric stenosis	274 <b>13.3</b>	14 <b>9.0</b>	188 <b>17.4</b>	3 <b>2.6</b>	6 <b>24.1</b>	487 <b>14.1</b>		
Rectal and large intestinal atresia/stenosis		7	81	4	3	213		
	5.1	4.5	7.5	3.4	12.1	6.1		
Reduction deformity, lower limbs	33 <b>1.6</b>	2 1.3	7 <b>0.6</b>	2 1.7	1 <b>4.0</b>	52 <b>1.5</b>		
Reduction deformity, upper limbs	50	3	31	1.7	1	1.0		
Reduction deformity, upper minos	2.4	1.9	2.9	0.9	4.0	2.9		
Renal agenesis/hypoplasia	98	10	51	2	1	183		
2 31 1	4.8	6.5	4.7	1.7	4.0	5.3		
Spina bifida without anencephalus	63 <b>3.1</b>	3 1.9	43 <b>4.0</b>	2 1.7	2 <b>8.0</b>	122 <b>3.5</b>	6	
Tetralogy of Fallot	80	8	38	8	0	134		
reduiogy of runot	3.9	5.2	3.5	6.9	0.0	3.9		
Total anomalous pulmonary venous return	13	1	24	0	0	38		
(TAPVR)	0.6	0.6	2.2	0.0	0.0	1.1		
Transposition of great arteries - All	65	5	37	3	1	117		
	3.2	3.2	3.4	2.6	4.0	3.4		
dextro-Transposition of great arteries	46	3	20	2	0	75		
(d-TGA)	2.2	1.9	1.9	1.7	0.0	2.2	7	
Tricuspid valve atresia and stenosis	23 1.1	4 2.6	22 <b>2.0</b>	1 <b>0.9</b>	0 <b>0.0</b>	53 <b>1.5</b>	7	
Trisomy 13	22	1	14	1	1	89		
11130Hiy 13	1.1	0.6	1.3	0.9	4.0	2.6		
Trisomy 18	35	3	33	5	0	164		
,	1.7	1.9	3.1	4.3	0.0	4.7		
Ventricular septal defect	912	81	544	45	14	1629	8	
	44.3	52.3	50.4	38.5	56.3	47.0		
Total Live Births	206083	15479	107852	11676	2486	346517		
<b>Total Male Live Births</b>	105866	7919	55352	5903	1255	177794		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

Colorado Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35	35+	Total	Notes			
Down syndrome (Trisomy 21)	317 <b>10.9</b>	374 <b>67.8</b>	715 <b>20.6</b>				
Trisomy 13	47 <b>1.6</b>	37 <b>6.</b> 7	89 <b>2.6</b>				
Trisomy 18	73 <b>2.5</b>	83 <b>15.1</b>	164 <b>4.</b> 7				
Total Live Births	291331	55140	346517				

<sup>\*\*</sup>Total includes unknown maternal age

- 1. Anencephalus: live births and fetal deaths any gestational age
- 2.Atrioventricular septal defect:Cannot include Inlet VSD
- 3.Gastroschisis: medical record review
- 4.Omphalocele: medical record review
- 5.Patent ductus arteriosus: birth weight greater than or equal to 2500 grams 6.Spina bifidia without anencephalus: live birth and fetal deaths any gestational age
- 7. Tricuspid valve atresia and stenosis: Tricuspid stenosis and hypoplasia included
- 8. Ventricular septal defects: includes probable cases

- -CDPHE (Colorado Department of Public Health and Environment) disclaims responsibility for any analysis, interpretations, or conclusions.
- -Contact State Program directly in regards to fetal alcohol syndrome
- -Medicaid added as a data source starting with the 2009 data year.
- -Reports of criticial congenital heart categories have been confirmed/invalidated for this time period

Delaware Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Amniotic bands	1 <b>0.5</b>	2	2	0 <b>0.0</b>	0 <b>0.0</b>	5		
Anencephalus	2	<b>2.1</b>	<b>3.7</b> 3	0.0	0.0	<b>1.4</b> 7		
	1.0	1.0	5.6	0.0	0.0	2.0		
Aniridia	0.5	0 <b>0.0</b>	1 <b>1.9</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.6</b>		
Anophthalmia/microphthalmia	2	0	0	1	0	3		
Anotia/microtia	1.0 9	<b>0.0</b> 2	<b>0.0</b> 7	<b>6.4</b> 0	<b>0.0</b> 0	<b>0.8</b> 18		
	4.7	2.1	13.0	0.0	0.0	5.0		
Aortic valve stenosis	8 <b>4.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>6.4</b>	0 <b>0.0</b>	9 <b>2.5</b>	1	
Atrial septal defect	48	22	16	0	0	86	2	
Atrioventricular septal defect	<b>25.1</b> 14	<b>22.9</b> 3	<b>29.</b> 7	<b>0.0</b> 0	0.0	<b>24.0</b> 19		
(endocardial cushion defect)	7.3	3.1	3.7	0.0	0.0	5.3		
Biliary atresia	1	1	0	0	0	2		
Choanal atresia	<b>0.5</b> 2	1.0 0	<b>0.0</b> 0	<b>0.0</b> 0	0.0	<b>0.6</b> 2		
	1.0	0.0	0.0	0.0	0.0	0.6		
Cleft lip with and without cleft palate	18 <b>9.4</b>	4 4.2	4 7.4	2 12.7	0 <b>0.0</b>	29 <b>8.1</b>		
Cleft palate without cleft lip	16	4	4	2	0	26	3	
Coarctation of aorta	<b>8.4</b> 5	<b>4.2</b> 3	7.4 0	12.7 0	0.0	7.3 8		
	2.6	3.1	0.0	0.0	0.0	2.2		
Common truncus	1 <b>0.5</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.3</b>		
Congenital cataract	6	1	4	1	0.0	12		
Committed him distances	3.1 63	<b>1.0</b> 5	7.4 9	<b>6.4</b> 4	<b>0.0</b>	<b>3.4</b> 82		
Congenital hip dislocation	32.9	5.2	16.7	25.4	0.0	22.9		
Diaphragmatic hernia	3	0	2 <b>3.</b> 7	1	0 <b>0.0</b>	6 <b>1.</b> 7		
Down syndrome (Trisomy 21)	<b>1.6</b> 28	<b>0.0</b> 7	4	<b>6.4</b> 4	0.0	43	4	
	14.6	7.3	7.4	25.4	0.0	12.0		
Ebstein anomaly	3 1.6	1 1.0	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 1.1		
Encephalocele	2	2	0	0	0	4		
Epispadias	<b>1.0</b>	<b>2.1</b> 0	0.0	<b>0.0</b> 0	0.0	1.1 2		
• •	0.5	0.0	0.0	0.0	0.0	0.6		
Esophageal atresia/tracheoesophageal fistula	3 <b>1.6</b>	1 <b>1.0</b>	2 <b>3.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	6 1.7		
Fetus or newborn affected by maternal	1	0	0	0	0	1		
alcohol use Gastroschisis	0.5	0.0	0.0	0.0	0.0	0.3		
	14 7.3	4 4.2	4 7. <b>4</b>	0 <b>0.0</b>	0 <b>0.0</b>	22 <b>6.1</b>		
Hirschsprung disease (congenital	4	1	2	0	0	7		
megacolon) Hydrocephalus without spina bifida	<b>2.1</b> 8	<b>1.0</b>	3.7 1	<b>0.0</b> 1	<b>0.0</b> 0	<b>2.0</b> 12	5	
• •	4.2	1.0	1.9	6.4	0.0	3.4		
Hypoplastic left heart syndrome	5 <b>2.6</b>	4.2	6 11.1	0 <b>0.0</b>	0 <b>0.0</b>	15 <b>4.2</b>		
Hypospadias*	85	43	7	6	1	145		
Microcephalus	<b>86.8</b> 8	<b>88.3</b> 12	<b>25.8</b> 2	73.3 4	<b>434.8</b>	<b>79.4</b> 30	6	
	4.2	12.5	3.7	25.4	200.0	8.4	U	
Obstructive genitourinary defect	201 <b>105.0</b>	54 <b>56.2</b>	39 <b>72.3</b>	22 <b>139.9</b>	0 <b>0.0</b>	317 <b>88.5</b>	7	
Omphalocele	103.0	4	0	0	0	5		
	0.5	4.2	0.0	0.0	0.0	1.4	0	
Patent ductus arteriosus	18 <b>9.4</b>	17 <b>17.7</b>	6 11.1	0 <b>0.0</b>	0 <b>0.0</b>	41 <b>11.4</b>	8	

**Delaware** Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Pulmonary valve atresia and stenosis	30 15.7	17 17.7	2 3.7	1 <b>6.4</b>	0 <b>0.0</b>	50 <b>14.0</b>	9	
Pyloric stenosis	25 <b>13.1</b>	3 <b>3.1</b>	9 <b>16.7</b>	2 12.7	0 <b>0.0</b>	40 11.2		
Rectal and large intestinal atresia/stenosis	10 5.2	2 <b>2.1</b>	2 3.7	0 <b>0.0</b>	0 <b>0.0</b>	15 <b>4.2</b>		
Reduction deformity, lower limbs	0 <b>0.0</b>	3 <b>3.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.8</b>		
Reduction deformity, upper limbs	5 <b>2.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	5 1.4		
Renal agenesis/hypoplasia	13 <b>6.8</b>	6 <b>6.2</b>	6 11.1	1 <b>6.4</b>	0 <b>0.0</b>	26 7.3		
Spina bifida without anencephalus	5 <b>2.6</b>	4 4.2	1 1.9	0 <b>0.0</b>	0 <b>0.0</b>	11 3.1	11	
Tetralogy of Fallot	10 <b>5.2</b>	2 <b>2.1</b>	2 3.7	3 <b>19.1</b>	0 <b>0.0</b>	17 <b>4.</b> 7	12	
Total anomalous pulmonary venous return (TAPVR)	1.6	1 1.0	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 1.1		
Transposition of great arteries - All	6 <b>3.1</b>	3 <b>3.1</b>	4 7. <b>4</b>	0 <b>0.0</b>	0 <b>0.0</b>	13 <b>3.6</b>		
Tricuspid valve atresia and stenosis	0 <b>0.0</b>	4 4.2	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 1.1	1	
Trisomy 13	1 <b>0.5</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.3</b>	4	
Trisomy 18	4 2.1	3 3.1	2 3.7	1 <b>6.4</b>	0 <b>0.0</b>	10 <b>2.8</b>	4	
Ventricular septal defect	157 <b>82.0</b>	65 <b>67.6</b>	45 <b>83.4</b>	10 <b>63.6</b>	1 200.0	280 <b>78.2</b>	15	
<b>Total Live Births</b>	19138	9616	5396	1572	50	35819		
<b>Total Male Live Births</b>	9796	4872	2718	818	23	18253		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

# **Delaware Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)**

Age							
Defect	Less than 35	35 and greater	Total**	Notes			
Down syndrome (Trisomy 21)	23 7.4	19 <b>38.5</b>	43 <b>12.0</b>	4			
Trisomy 13	0 <b>0.0</b>	1 <b>2.0</b>	1 <b>0.3</b>	4			
Trisomy 18	5 <b>1.6</b>	5 10.1	10 <b>2.8</b>	4			
Total Live Births	30890	4929	35819				

<sup>\*\*</sup>Total includes unknown maternal age

### Notes

- 1. Trivial or limited are not included.
- 2.Atrial septal fenestrations are reported as an atrial septal defect (ASD). ASDs that self-close (not present after a month) are considered Patent Foramen Ovales (PFO). PFOs are not counted.
- 3. Pierre Robin sequence defects are included as a cleft palate.
- 4.All chromosomal defects require a cytogenetics report.
- 5.Benign external hydrocephalus or hydrocephalus due to a secondary cause are not included.
- 6.Head circumference must be less than the 5th percentile.
- 7.All obstructive and non-obstructive genitourinary defects (i.e., all hydronephrosis and other types of kidney dilation) are included as well as all resolved defects that were confirmed postnatally.
- 8. The newborn must weigh 2500 grams or greater and the PDA must be present at one month of age.
- 9. Peripheral, branch, trivial, or limited are not included.
- 10.Delaware did not perform CCHD screening in 2007, 2008, and 2009; Peripheral, branch, trivial, or limited are not included.
- 11. Spina bifida occulta is not included.
- 12.A ventricular septal defect with an overriding aorta is counted as Tetralogy of Fallot.
- 13.Delaware did not perform CCHD screening in 2007, 2008, and 2009.

- -2007 Maternal Fetal Medicine (MFM) cases were derived from cytogenetic lists and fetal therapy lists. 2008 MFM cases were derived from all possible defect cases handled by MFM. 2009 MFM cases were derived from cytogenetic lists only.
- -All defects found prenatally must be confirmed postnatally or through cytogenetic testing.
- -All heart defects require an echocardiogram report.
- -Coding system used was CDC/BPA.
- -Fetal deaths (including terminations) are included if the fetus weighed 350 grams or higher; in the absence of weight at least 20 weeks gestation or greater.
- -Registry does not distinguish spontaneous terminations from elective terminations. Stillbirths, miscarriages, and terminations are all currently reported together.
- -Registry was not collecting data in 2006. Registry data from 2010 is currently being vetted.

Florida Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
<u>D</u> efect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Anencephalus	30 <b>0.6</b>	16 <b>0.6</b>	12 <b>0.4</b>	0 <b>0.0</b>	0 <b>0.0</b>	62 <b>0.5</b>	1	
Aniridia	2	3	1	0	0	6		
Anophthalmia/microphthalmia	<b>0.0</b> 47	<i>0.1</i> 24	<b>0.0</b> 23	<b>0.0</b> 1	0.0	<b>0.1</b> 96		
Anophthainna/inicrophthainna	0.9	1.0	0.7	0.3	0.0	0.8		
Anotia/microtia	37 <b>0.</b> 7	5 <b>0.2</b>	32 <b>1.0</b>	3 1.0	1 <b>4.5</b>	79 <b>0.</b> 7		
Aortic valve stenosis	101	21	34	4	1	163		
Atrioventricular septal defect	2.0 200	<b>0.9</b> 119	<b>1.0</b> 105	1.3 17	<b>4.5</b> 0	<b>1.4</b> 452	2	
(endocardial cushion defect)	<b>4.0</b>	4.8	3.2	5.5	0.0	4.0	2	
Biliary atresia	39 <b>0.8</b>	44 <b>1.8</b>	23 <b>0.</b> 7	3 <b>1.0</b>	1 4.5	114 <b>1.0</b>		
Bladder exstrophy	15	9	8	0	0	32		
Channal atracia	0.3	0.4	0.2	0.0	0.0	0.3		
Choanal atresia	87 <b>1.7</b>	27 <b>1.1</b>	44 1.3	5 <b>1.6</b>	0 <b>0.0</b>	166 <b>1.5</b>		
Cleft lip with and without cleft palate	478 <b>9.5</b>	123 <b>5.0</b>	217	27 <b>8.</b> 7	1 <b>4.5</b>	856 7.5		
Cleft palate without cleft lip	338	121	<b>6.6</b> 159	19	0	645		
	6.7	4.9	4.9	6.2	0.0	5.7		
Coarctation of aorta	402 <b>8.0</b>	135 <b>5.5</b>	192 <b>5.9</b>	15 <b>4.9</b>	3 13.5	767 <b>6.</b> 7		
Common truncus	55	15	21	3	0	95		
Congenital cataract	<b>1.1</b> 75	<b>0.6</b> 37	<b>0.6</b> 29	<b>1.0</b> 2	0.0	<b>0.8</b> 144		
	1.5	1.5	0.9	0.6	0.0	1.3		
Congenital hip dislocation	483 <b>9.6</b>	98 <b>4.0</b>	276 <b>8.4</b>	28 <b>9.1</b>	4 17.9	902 7. <b>9</b>		
Diaphragmatic hernia	169	90	83	6	0	364		
Down syndrome (Trisomy 21)	<b>3.3</b> 667	<b>3.6</b> 314	<b>2.5</b> 423	1.9 45	<b>0.0</b> 4	3.2 1483	1	
	13.2	12.7	12.9	14.6	17.9	13.0		
Ebstein anomaly	38 <b>0.8</b>	14 <b>0.6</b>	14 <b>0.4</b>	2 <b>0.6</b>	1 4.5	70 <b>0.6</b>		
Encephalocele	35	33	28	2	0	100		
Epispadias	<b>0.7</b> 81	1.3 23	<b>0.9</b> 25	<b>0.6</b> 1	<b>0.0</b> 0	<b>0.9</b> 133		
	1.6	0.9	0.8	0.3	0.0	1.2		
Esophageal atresia/tracheoesophageal fistula	120 <b>2.4</b>	48 <b>1.9</b>	72 <b>2.2</b>	2 <b>0.6</b>	0 <b>0.0</b>	247 2.2		
Gastroschisis	310	70	111	7	0	504	3	
Hirschsprung disease (congenital	<b>6.1</b> 141	<b>2.8</b> 99	<b>3.4</b> 66	2.3 4	<b>0.0</b> 0	<b>4.4</b> 316		
megacolon)	2.8	4.0	2.0	1.3	0.0	2.8		
Hydrocephalus without spina bifida	302 <b>6.0</b>	281 <b>11.4</b>	191 <b>5.8</b>	19 <b>6.2</b>	1 <b>4.5</b>	810 <b>7.1</b>		
Hypoplastic left heart syndrome	171	93	80	4	0	355		
Hypospadias*	<b>3.4</b> 2199	<b>3.8</b> 808	<b>2.4</b> 790	1.3 80	<b>0.0</b> 3	<b>3.1</b> 3971		
Hypospadias**	85.0	64.2	790 <b>47.1</b>	50.2	25.8	68.2		
Microcephalus	293	219	189	12	3	724		
Obstructive genitourinary defect	<b>5.8</b> 1918	<b>8.9</b> 734	<b>5.8</b> 1438	<b>3.9</b> 109	<b>13.5</b> 5	<b>6.4</b> 4301		
	38.0	29.7	43.9	35.3	22.4	37.8	1	
Omphalocele	25 <b>0.5</b>	19 <b>0.8</b>	10 <b>0.3</b>	1 <b>0.3</b>	0 <b>0.0</b>	57 <b>0.5</b>	4	
Pulmonary valve atresia and stenosis	484	322	291	20	3	1137		
Pulmonary valve atresia	<b>9.6</b> 78	<b>13.0</b> 47	<b>8.9</b> 43	<b>6.5</b> 5	13.5 0	10.0 175		
	1.5	1.9	1.3	1.6	0.0	1.5		
Pyloric stenosis	1829 <b>36.2</b>	403 <b>16.3</b>	777 <b>23.</b> 7	16 <b>5.2</b>	1 <b>4.5</b>	3066 <b>27.0</b>		

Florida Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Rectal and large intestinal atresia/stenosis	220 4.4	121 <b>4.9</b>	119 <b>3.6</b>	11 3.6	1 4.5	485 <b>4.3</b>		
Reduction deformity, lower limbs	77 1.5	47 <b>1.9</b>	47 1.4	4 1.3	0 <b>0.0</b>	179 <b>1.6</b>		
Reduction deformity, upper limbs	135 2.7	57 <b>2.3</b>	52 <b>1.6</b>	4 1.3	0	249 2.2		
Renal agenesis/hypoplasia	244 <b>4.8</b>	105 4.3	123 3.8	10 3.2	1 4.5	491 <b>4.3</b>		
Spina bifida without anencephalus	145 <b>2.9</b>	64 <b>2.6</b>	96 <b>2.9</b>	5 1.6	0 <b>0.0</b>	314 <b>2.8</b>	1	
Tetralogy of Fallot	271 <b>5.4</b>	123 5.0	112 3.4	19 <b>6.2</b>	1 4.5	540 <b>4.</b> 7		
Total anomalous pulmonary venous return (TAPVR)	1 40 <b>0.8</b>	31 1.3	25 <b>0.8</b>	6 <b>1.9</b>	0 <b>0.0</b>	103 <b>0.9</b>		
Transposition of great arteries - All	243 <b>4.8</b>	109 <b>4.4</b>	133 <b>4.1</b>	8 <b>2.6</b>	0 <b>0.0</b>	503 <b>4.4</b>		
dextro-Transposition of great arteries (d-TGA)	145 <b>2.9</b>	39 <b>1.6</b>	70 <b>2.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	261 2.3		
Tricuspid valve atresia and stenosis	61 1.2	29 1.2	30 <b>0.9</b>	1 <b>0.3</b>	0 <b>0.0</b>	125 1.1	2	
Trisomy 13	42 <b>0.8</b>	32 1.3	23 <b>0.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	100 <b>0.9</b>	1	
Trisomy 18	80 <b>1.6</b>	67 <b>2.</b> 7	59 <b>1.8</b>	6 <b>1.9</b>	0 <b>0.0</b>	217 <b>1.9</b>	1	
Ventricular septal defect	2863 <b>56.</b> 7	1283 <b>52.0</b>	1985 <b>60.6</b>	147 <b>47.6</b>	8 <b>35.9</b>	6394 <b>56.2</b>	2	
<b>Total Live Births</b>	504621	246756	327639	30885	2230	1137228		
<b>Total Male Live Births</b>	258581	125827	167780	15931	1163	582127		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Florida Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	35	35+	Total	Notes			
Down syndrome (Trisomy 21)	782 <b>8.1</b>	701 <b>42.1</b>	1483 1 <b>3.0</b>	1			
Trisomy 13	66 <b>0.</b> 7	34 <b>2.0</b>	100 <b>0.9</b>	1			
Trisomy 18	128 <b>1.3</b>	89 <b>5.3</b>	217 <b>1.9</b>	1			
Total Live Births	970738	166443	1137228				

<sup>\*\*</sup>Total includes unknown maternal age

- 1.Florida reports live births only 2.Includes probable cases
- 3.Cases of Gastroschisis were differentiated from Omphalocele by using 54.71 procedure code in 2006-2009 and the 756.73 ICD-9-CM code in 2010

-Atrial Septal Defect, Fetus or newborn affected by maternal alcohol use and patent ductus arteriosus are not reported

<sup>4.</sup> Reported for 2009 and 2010 only using the ICD-9- $\hat{\text{CM}}$  code 756.72

Georgia Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Amniotic bands	6 <b>0.8</b>	25 2.4	4 0.6	2 1.2	0 <b>0.0</b>	37 1.4		
Anencephalus	16	30	18	2	0	74		
Aniridia	<b>2.1</b>	<b>2.9</b> 3	<b>2.9</b> 1	1.2 0	0.0	<b>2.8</b> 7		
Anophthalmia/microphthalmia	<b>0.1</b> 4	<b>0.3</b> 12	<b>0.2</b> 10	<b>0.0</b> 2	<b>0.0</b> 0	<b>0.3</b> 31		
	0.5	1.2	1.6	1.2	0.0	1.2		
Anotia/microtia	8 1.1	13 1.3	14 2.2	0 <b>0.0</b>	0 <b>0.0</b>	38 1.4		
Aortic valve stenosis	20 2.7	16 <b>1.6</b>	6 <b>1.0</b>	1 <b>0.6</b>	0 <b>0.0</b>	46 <b>1.</b> 7		
Atrial septal defect	168	195	128	14	0	532		
Atrioventricular septal defect	<b>22.4</b> 43	<b>19.0</b> 86	<b>20.3</b> 30	<b>8.6</b> 2	<b>0.0</b>	<b>19.9</b> 178		
(endocardial cushion defect) Biliary atresia	5.7 3	<b>8.4</b> 12	<b>4.8</b> 2	1.2 0	<b>39.1</b> 0	<b>6.6</b> 19		
	0.4	1.2	0.3	0.0	0.0	0.7		
Bladder exstrophy	2 <b>0.3</b>	2 <b>0.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 <b>0.1</b>		
Choanal atresia	8 1.1	10 <b>1.0</b>	0 <b>0.0</b>	1 <b>0.6</b>	0 <b>0.0</b>	20 <b>0.</b> 7		
Cleft lip with and without cleft palate	68	89	59	8	6	244		
Cleft palate without cleft lip	<b>9.1</b> 35	<b>8. 7</b> 49	<b>9.4</b> 40	<b>4.9</b> 5	<b>234.4</b> 2	<b>9.1</b> 138		
Coarctation of aorta	<b>4. 7</b> 44	<b>4.8</b> 43	<b>6.3</b> 26	<b>3.1</b> 3	<b>78.1</b> 0	<b>5.2</b> 127		
	5.9	4.2	4.1	1.8	0.0	4.7		
Common truncus	10 1.3	17 <b>1.7</b>	4 <b>0.6</b>	1 <b>0.6</b>	0 <b>0.0</b>	34 1.3		
Congenital cataract	16 <b>2.1</b>	17 <b>1.</b> 7	9 <b>1.4</b>	2 1.2	0 <b>0.0</b>	44 <b>1.6</b>		
Congenital hip dislocation	82 10.9	25 2.4	49 7.8	2 1.2	1 39.1	172 <b>6.4</b>		
Diaphragmatic hernia	20	23	22	2	1	80		
Down syndrome (Trisomy 21)	2.7 173	2.2 165	3.5 127	1.2 25	<i>39.1</i> 2	<b>3.0</b> 535		
Ebstein anomaly	23.0	16.1 3	<b>20.2</b> 7	<b>15.4</b> 1	<b>78.1</b> 0	<b>20.0</b> 16		
·	4 <b>0.</b> 5	0.3	1.1	0.6	0.0	0.6		
Encephalocele	0 <b>0.0</b>	13 <b>1.3</b>	4 <b>0.6</b>	5 <b>3.1</b>	1 <b>39.1</b>	29 <b>1.1</b>		
Epispadias	4	6	1	0	0	11		
Esophageal atresia/tracheoesophageal	<b>0.5</b> 28	<b>0.6</b> 20	<b>0.2</b> 7	<b>0.0</b> 0	0.0	<b>0.4</b> 58		
fistula Fetus or newborn affected by maternal	<b>3.7</b> 5	1.9 3	<b>1.1</b>	<b>0.0</b> 0	<b>0.0</b>	<b>2.2</b> 9		
alcohol use	<b>0.</b> 7	0.3	0.2	0.0	0.0	0.3		
Gastroschisis	29 <b>3.9</b>	50 <b>4.9</b>	28 <b>4.4</b>	5 <b>3.1</b>	0 <b>0.0</b>	120 <b>4.5</b>		
Hirschsprung disease (congenital megacolon)	10 <b>1.3</b>	33 <b>3.2</b>	3 <b>0.5</b>	0 <b>0.0</b>	1 <b>39.1</b>	50 <b>1.9</b>		
Hydrocephalus without spina bifida	74	120	39	11	3	281		
Hypoplastic left heart syndrome	<b>9.9</b> 20	11.7 16	<b>6.2</b> 10	<b>6.8</b> 3	117.2 0	<b>10.5</b> 55		
Hypospadias*	2.7 328	1.6 328	<b>1.6</b> 80	1.8 23	<b>0.0</b> 2	<b>2.1</b> 798		
	85.0	62.7	24.8	27.4	146.0	58.2		
Microcephalus	26 3.5	73 7.1	29 <b>4.6</b>	3 1.8	1 <b>39.1</b>	139 <b>5.2</b>		
Obstructive genitourinary defect	414 55.1	350 <b>34.1</b>	278 <b>44.1</b>	34 <b>20.9</b>	12 <b>468.8</b>	1188 <b>44.4</b>		
Omphalocele	19 2.5	34 3.3	15 2.4	1 0.6	1 39.1	78 <b>2.9</b>		

Georgia Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Patent ductus arteriosus	256	247	163	17	6	727	1	
	34.1	24.0	25.9	10.5	234.4	27.2		
Pulmonary valve atresia and stenosis	48	75 7.3	38	9	1	183		
Dl	6.4	7.3 20	6.0	5.5 1	39.1	6.8		
Pulmonary valve atresia	12 <b>1.6</b>	1.9	14 2.2	<b>0.6</b>	0 <b>0.0</b>	55 <b>2.1</b>		
Pyloric stenosis	111	59	95	5	0.0	292		
1 yione stenosis	14.8	5.7	15.1	3.1	0.0	10.9		
Rectal and large intestinal atresia/stenosis		33	37	9	0	113		
	3.2	3.2	5.9	5.5	0.0	4.2		
Reduction deformity, lower limbs	14	24	12	0	0	54		
·	1.9	2.3	1.9	0.0	0.0	2.0		
Reduction deformity, upper limbs	14	35	15	1	0	73		
	1.9	3.4	2.4	0.6	0.0	2.7		
Renal agenesis/hypoplasia	49	60	26	3	1	149		
0 : 1:01 :4	6.5	5.8	4.1	1.8	39.1	5.6		
Spina bifida without anencephalus	40 5.3	35 <b>3.4</b>	29 <b>4.6</b>	4 2.5	0 <b>0.0</b>	117 <b>4.4</b>		
Tetralogy of Fallot	42	51	13	2.3 7	0.0	124		
Tettalogy of Fallot	5.6	<b>5.0</b>	2.1	4.3	0.0	4.6		
Total anomalous pulmonary venous return		10	10	2	0.0	31		
(TAPVR)	0.9	1.0	1.6	1.2	0.0	1.2		
Transposition of great arteries - All	34	38	15	2	0	91		
	4.5	<b>3.</b> 7	2.4	1.2	0.0	3.4		
dextro-Transposition of great arteries	32	30	12	2	0	78		
(d-TGA)	4.3	2.9	1.9	1.2	0.0	2.9		
Tricuspid valve atresia and stenosis	11	23	8	2	0	54		
m: 11 1 4 1	1.5	2.2	1.3	1.2	0.0	2.0		
Tricuspid valve atresia	7 <b>0.9</b>	18 <b>1.8</b>	4 <b>0.6</b>	1 <b>0.6</b>	0 <b>0.0</b>	31 1.2		
Trisomy 13	13	24	3	0.0	0.0	45		
Trisonly 13	1.7	2.3	0.5	0.0	0.0	1.7		
Trisomy 18	47	33	17	10	1	131		
	6.3	3.2	2.7	6.2	39.1	4.9		
Ventricular septal defect	516	437	346	40	6	1421		
ī	<b>68.</b> 7	42.5	54.9	24.6	234.4	53.1		
<b>Total Live Births</b>	75115	102735	63007	16259	256	267700		
<b>Total Male Live Births</b>	38594	52299	32280	8402	137	137034		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Georgia Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35	35+	Total**	Notes			
Down syndrome (Trisomy 21)	257 <b>11.8</b>	259 <b>51.0</b>	535 <b>20.0</b>				
Trisomy 13	28 <b>1.3</b>	17 <b>3.3</b>	45 <b>1.</b> 7				
Trisomy 18	40 1.8	89 17.5	131 <b>4.9</b>				
<b>Total Live Births</b>	216932	50765	267700				

<sup>\*\*</sup>Total includes unknown maternal age

1. Cases included if gestational age at birth was greater than or equal to 36 weeks and PDA was last noted at >=6 weeks of age; or if gestational age at birth was greater than or equal to 36 weeks and PDA noted at < 6wks of age was treated or if another heart defect was present

- -All totals include definite, probable/possible, and prenatal diagnoses
- -All totals include live births and stillbirths greater than or equal to 20 weeks, elective terminations at any gestational age, and prenatal diagnoses with undocumented outcome at any gestational age.
- -Georgia uses CDC/BPA codes
  -NCHS bridged race data were not available. Multiple-race individuals are included in the totals only.

Illinois Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Amniotic bands	53 1.2	19 1.3	9 <b>0.4</b>	3 <b>0.6</b>	0 <b>0.0</b>	85 1.0		
Anencephalus	67	24	31	5	0	127		
Aniridia	<b>1.5</b>	1.6 0	1.5 1	1.1 0	<b>0.0</b> 0	1.5 2		
	0.0	0.0	0.0	0.0	0.0	0.0		
Anophthalmia/microphthalmia	59 <b>1.3</b>	12 <b>0.8</b>	20 1.0	8 1.7	0 <b>0.0</b>	100 <b>1.1</b>		
Anotia/microtia	66 <b>1.4</b>	9 <b>0.6</b>	38 <b>1.8</b>	8 1.7	0 <b>0.0</b>	124 <b>1.4</b>		
Aortic valve stenosis	72	8	4	2	0	87		
Atrial septal defect	1.6 1272	<b>0.5</b> 450	<b>0.2</b> 248	<b>0.4</b> 73	2	1.0 2074		
	27.7	29.7	11.9	15.7	16.2	23.8		
Atrioventricular septal defect (endocardial cushion defect)	265 <b>5.8</b>	83 <b>5.5</b>	42 <b>2.0</b>	4 <b>0.9</b>	0 <b>0.0</b>	399 <b>4.6</b>		
Biliary atresia	9 <b>0.2</b>	3 <b>0.2</b>	1 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	13 <b>0.1</b>		
Bladder exstrophy	19	2	1	0	0	22		
Choanal atresia	<b>0.4</b> 57	<b>0.1</b> 15	<b>0.0</b> 10	<b>0.0</b> 4	0.0	<b>0.3</b> 87		
	1.2	1.0	0.5	0.9	0.0	1.0		
Cleft lip with and without cleft palate	507 <b>11.0</b>	89 <b>5.9</b>	85 <b>4.1</b>	36 7.7	2 16.2	724 <b>8.3</b>		
Cleft palate without cleft lip	301	46	50 <b>2.4</b>	20	0	422		
Coarctation of aorta	<b>6.6</b> 169	<b>3.0</b> 33	36	<b>4.3</b> 5	<b>0.0</b> 0	<b>4.8</b> 247		
Common truncus	3.7 25	2.2 9	1.7 2	1.1 1	0.0	<b>2.8</b> 37		
	0.5	0.6	0.1	0.2	0.0	0.4		
Congenital cataract	40 <b>0.9</b>	18 1.2	7 <b>0.3</b>	1 <b>0.</b> 2	0 <b>0.0</b>	67 <b>0.8</b>		
Congenital hip dislocation	208	12	20	11 2.4	0 <b>0.0</b>	252 <b>2.9</b>		
Diaphragmatic hernia	<b>4.5</b> 128	<b>0.8</b> 39	<b>1.0</b> 16	10	0.0	196		
Down syndrome (Trisomy 21)	<b>2.8</b> 753	<b>2.6</b> 149	<b>0.8</b> 165	<b>2.1</b> 39	<b>0.0</b>	2.3 1121		
	16.4	9.8	7.9	8.4	8.1	12.9		
Ebstein anomaly	31 <b>0.</b> 7	3 <b>0.2</b>	7 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	41 <b>0.5</b>		
Encephalocele	28	18	15	2	0	63		
Epispadias	<b>0.6</b> 76	1.2 20	<b>0.7</b> 5	<b>0.4</b> 0	<b>0.0</b>	<b>0.7</b> 101		
	<i>1.7</i>	1.3	0.2	0.0	0.0	1.2		
Esophageal atresia/tracheoesophageal fistula	132 <b>2.9</b>	23 <b>1.5</b>	20 1.0	7 <b>1.5</b>	0 <b>0.0</b>	184 <b>2.1</b>		
Fetus or newborn affected by maternal alcohol use	9 <b>0.2</b>	7 <b>0.5</b>	1 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	17 <b>0.2</b>		
Gastroschisis	232	64	47	5	0	349		
Hirschsprung disease (congenital	<b>5.1</b> 50	<b>4.2</b> 21	<b>2.3</b> 10	<i>1.1</i> 4	0.0	<b>4.0</b> 85		
megacolon)	1.1	1.4	0.5	0.9	0.0	1.0		
Hydrocephalus without spina bifida	343 7.5	180 11.9	83 <b>4.0</b>	26 <b>5.6</b>	0 <b>0.0</b>	637 7.3		
Hypoplastic left heart syndrome	106 <b>2.3</b>	31 <b>2.0</b>	17 <b>0.8</b>	7 1.5	0 <b>0.0</b>	161 <b>1.8</b>		
Hypospadias*	1615	380	105	84	1	2207		
Microcephalus	<b>68.6</b> 207	<b>49.4</b> 125	<b>9.9</b> 48	<b>35.1</b> 8	15.5 0	<b>49.6</b> 392		
•	4.5	8.2	2.3	<i>1.7</i>	0.0	4.5		
Obstructive genitourinary defect	1615 35.2	354 <b>23.4</b>	242 <b>11.6</b>	133 <b>28.6</b>	1 <b>8.1</b>	2361 27.1		
Omphalocele	89	29	19	3	0	140		
	1.9	1.9	0.9	0.6	0.0	1.6		

Illinois Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Patent ductus arteriosus	1201	349	230	70	1	1866	1
Pulmonary valve atresia and stenosis	26.2 130 2.8	23.0 52 3.4	11.0 21 1.0	7 1.5	<b>8.1</b> 0 <b>0.0</b>	21.4 211 2.4	
Pulmonary valve atresia	23 0.5	11 <b>0.</b> 7	5 <b>0.2</b>	1 0.2	0 <b>0.0</b>	41 <b>0.5</b>	
Pyloric stenosis	30 <b>0.</b> 7	6 <b>0.4</b>	4 <b>0.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	40 <b>0.5</b>	
Rectal and large intestinal atresia/stenosis	187 <b>4.1</b>	59 <b>3.9</b>	35 1.7	20 <b>4.3</b>	0 <b>0.0</b>	304 3.5	
Reduction deformity, lower limbs	81 <b>1.8</b>	20 1.3	10 <b>0.5</b>	5 <b>1.1</b>	0 <b>0.0</b>	116 1.3	
Reduction deformity, upper limbs	174 <b>3.8</b>	59 <b>3.9</b>	26 1.2	7 <b>1.5</b>	0 <b>0.0</b>	269 3.1	
Renal agenesis/hypoplasia	254 <b>5.5</b>	55 <b>3.6</b>	45 <b>2.2</b>	16 <b>3.4</b>	0 <b>0.0</b>	371 <b>4.3</b>	
Spina bifida without anencephalus	157 <b>3.4</b>	27 <b>1.8</b>	33 <b>1.6</b>	15 <b>3.2</b>	0 <b>0.0</b>	234 2.7	
Tetralogy of Fallot	163 <b>3.6</b>	51 <b>3.4</b>	32 <b>1.5</b>	19 <b>4.1</b>	0 <b>0.0</b>	267 <b>3.1</b>	
Total anomalous pulmonary venous return (TAPVR)	26 <b>0.6</b>	9 <b>0.6</b>	16 <b>0.8</b>	4 <b>0.9</b>	0 <b>0.0</b>	55 <b>0.6</b>	
Transposition of great arteries - All	103 2.2	25 <b>1.6</b>	27 <b>1.3</b>	9 <b>1.9</b>	0 <b>0.0</b>	167 <b>1.9</b>	
Tricuspid valve atresia and stenosis	66 1.4	24 <b>1.6</b>	16 <b>0.8</b>	5 <b>1.1</b>	1 <b>8.1</b>	113 <b>1.3</b>	
Trisomy 13	70 <b>1.5</b>	19 <b>1.3</b>	12 <b>0.6</b>	4 <b>0.9</b>	0 <b>0.0</b>	106 1.2	
Trisomy 18	109 <b>2.4</b>	35 <b>2.3</b>	36 1.7	11 <b>2.4</b>	0 <b>0.0</b>	192 <b>2.2</b>	
Ventricular septal defect	2283 <b>49.8</b>	487 <b>32.1</b>	378 <b>18.1</b>	116 <b>24.9</b>	3 <b>24.4</b>	3304 <b>38.0</b>	
<b>Total Live Births</b>	458879	151591	208756	46530	1232	870570	
<b>Total Male Live Births</b>	235264	76975	106106	23899	647	444716	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

Illinois Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)						
Defect	35	35+	Total	Notes		
Down syndrome (Trisomy 21)	551 <b>7.5</b>	559 <b>41.3</b>	1121 12.9			
Trisomy 13	70 <b>1.0</b>	32 <b>2.4</b>	106 <b>1.2</b>			
Trisomy 18	84 1.1	89 <b>6.6</b>	192 <b>2.2</b>			
<b>Total Live Births</b>	735034	135477	870570			

<sup>\*\*</sup>Total includes unknown maternal age

1.Only includes cases where the birth weight >=2500g

- -2010 birth (denominator) data are provisional.
  -Illinois is under court order that limits the data that can be collected about a termination. The birth defect registry is therefore unable to obtain birth defect information from terminations.
- -In 2009, Illinois reduced the number of charts that were reviewed for birth defects, dropping primarily children with very low-birth weights and no reported associated birth defects

Indiana Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Anencephalus	7 <b>0.2</b>	2 <b>0.4</b>	1 <b>0.3</b>	1 <b>1.0</b>	0 <b>0.0</b>	11 <b>0.3</b>		
Aniridia	10	3	1	0	0.0	<b>0.3</b> 14		
A h. dh l i - / i h. dh l i -	<i>0.3</i> 24	0.5	<b>0.3</b> 2	0.0	<b>0.0</b> 0	0.3		
Anophthalmia/microphthalmia	0.8	2 <b>0.4</b>	0.5	2 <b>2.1</b>	0.0	30 <b>0.</b> 7		
Anotia/microtia	33	3	2	0	0	39		
Aortic valve stenosis	<b>1.0</b> 47	<b>0.5</b> 4	<b>0.5</b>	<b>0.0</b> 1	0.0	<b>0.9</b> 57		
	1.5	0.7	1.0	1.0	0.0	1.3	1	
Atrial septal defect	1420 <b>44.5</b>	241 <b>42.8</b>	144 37.3	44 <b>45.4</b>	4 51.3	1891 <b>43.8</b>	1	
Atrioventricular septal defect	131	18	9	3	1	166	2	
(endocardial cushion defect) Biliary atresia	<b>4.1</b> 17	<b>3.2</b> 8	2.3	<b>3.1</b> 1	<b>12.8</b> 0	<b>3.8</b> 29		
	0.5	1.4	0.8	1.0	0.0	0.7		
Bladder exstrophy	15 <b>0.5</b>	1 0.2	1 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	18 <b>0.4</b>		
Choanal atresia	52	2	5	1	0.0	62		
	1.6	0.4	1.3	1.0	0.0	1.4		
Cleft lip with and without cleft palate	299 <b>9.4</b>	27 <b>4.8</b>	39 <b>10.1</b>	11 <b>11.3</b>	1 12.8	383 <b>8.9</b>		
Cleft palate without cleft lip	222	29	14	6	0	277		
Coarctation of aorta	7. <b>0</b> 207	<b>5.2</b> 19	<b>3.6</b> 23	<b>6.2</b> 5	<b>0.0</b>	<b>6.4</b> 258		
	6.5	3.4	6.0	5.2	12.8	6.0		
Common truncus	19 <b>0.6</b>	1 <b>0.2</b>	1 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	21 <b>0.5</b>		
Congenital cataract	21	7	1	1	0	32		
Congenital hip dislocation	<b>0.7</b> 254	<b>1.2</b> 14	<b>0.3</b> 26	<b>1.0</b> 8	<b>0.0</b>	<b>0.</b> 7 304		
Congenital inp dislocation	8.0	2.5	<b>6.</b> 7	8.2	0.0	7. <b>0</b>		
Diaphragmatic hernia	86 <b>2.</b> 7	16 <b>2.8</b>	15 <b>3.9</b>	2 <b>2.</b> 1	0 <b>0.0</b>	121 <b>2.8</b>		
Down syndrome (Trisomy 21)	403	37	53	15	1	515		
	12.6	6.6	13.7	15.5	12.8	11.9		
Ebstein anomaly	23 <b>0.</b> 7	1 <b>0.2</b>	1 <b>0.3</b>	1 1.0	0 <b>0.0</b>	26 <b>0.6</b>		
Encephalocele	24	1	4	1	0	30		
Epispadias	<i>0.8</i> 33	<b>0.2</b> 7	1.0	<b>1.0</b> 2	<b>0.0</b> 0	<b>0.7</b> 43	3	
• •	1.0	1.2	0.3	2.1	0.0	1.0	3	
Esophageal atresia/tracheoesophageal fistula	82 <b>2.6</b>	8 1.4	14 <b>3.6</b>	1 <b>1.0</b>	1 12.8	106 <b>2.5</b>		
Fetus or newborn affected by maternal	103	25	7	16	0	154		
alcohol use Gastroschisis	<b>3.2</b> 145	<b>4.4</b> 22	<b>1.8</b> 21	<b>16.5</b> 2	<b>0.0</b>	<b>3.6</b> 196	4	
Gastroschisis	4.5	3.9	5.4	2.1	0.0	4.5	<del>-</del>	
Hirschsprung disease (congenital megacolon)	63	13	13	1 <b>1.0</b>	0 <b>0.0</b>	93 <b>2.2</b>		
Hydrocephalus without spina bifida	<b>2.0</b> 151	<b>2.3</b> 43	<b>3.4</b> 16	6	1	2.2		
•	4.7	7.6	4.1	6.2	12.8	5.1		
Hypoplastic left heart syndrome	55 <b>1.</b> 7	12 <b>2.1</b>	8 <b>2.1</b>	2 <b>2.1</b>	1 12.8	79 <b>1.8</b>		
Hypospadias*	1159	122	50	14	1	1365	3	
Microcephalus	<b>70.9</b> 307	<b>42.9</b> 59	<b>25.4</b> 36	<b>27.9</b> 18	<b>26.9</b> 2	<b>61.8</b> 428		
	9.6	10.5	9.3	18.6	25.6	9.9		
Obstructive genitourinary defect	820 <b>25.</b> 7	116 <b>20.6</b>	84 <b>21.8</b>	20 <b>20.6</b>	2 <b>25.6</b>	1056 <b>24.5</b>		
Omphalocele	21	6	1	1	0	29	4	
	0.7	1.1	0.3	1.0	<b>0.0</b> 6	<b>0.7</b> 994	-	
Patent ductus arteriosus	666 <b>20.9</b>	191 <b>34.0</b>	83 <b>21.5</b>	26 <b>26.8</b>	76.9	23.0	5	

Indiana Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Pulmonary valve atresia and stenosis	237 7.4	45 <b>8.0</b>	22 <b>5.</b> 7	6 <b>6.2</b>	1 12.8	317 7.3	
Pyloric stenosis	912 <b>28.6</b>	80 14.2	105 27.2	7 7.2	5 <b>64.1</b>	1128 <b>26.2</b>	
Rectal and large intestinal atresia/stenosis	144 <b>4.5</b>	20 <b>3.6</b>	18 <b>4.</b> 7	5 <b>5.2</b>	1 12.8	189 <b>4.4</b>	
Reduction deformity, lower limbs	31 1.0	11 <b>2.0</b>	8 <b>2.1</b>	1 <b>1.0</b>	0 <b>0.0</b>	52 <b>1.2</b>	
Reduction deformity, upper limbs	92 <b>2.9</b>	12 <b>2.1</b>	12 <b>3.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	116 <b>2.</b> 7	
Renal agenesis/hypoplasia	111 3.5	10 <b>1.8</b>	13 <b>3.4</b>	2 2.1	0 <b>0.0</b>	138 3.2	
Spina bifida without anencephalus	153 <b>4.8</b>	14 2.5	18 <b>4.</b> 7	1 <b>1.0</b>	0 <b>0.0</b>	189 <b>4.4</b>	
Tetralogy of Fallot	89 <b>2.8</b>	14 2.5	12 <b>3.1</b>	2 2.1	0 <b>0.0</b>	119 <b>2.8</b>	
Total anomalous pulmonary venous return (TAPVR)	25 <b>0.8</b>	5 <b>0.9</b>	4 1.0	0 <b>0.0</b>	0 <b>0.0</b>	35 <b>0.8</b>	
Transposition of great arteries - All	155 <b>4.9</b>	18 <b>3.2</b>	13 <b>3.4</b>	0 <b>0.0</b>	0 <b>0.0</b>	194 <b>4.5</b>	6
Tricuspid valve atresia and stenosis	25 <b>0.8</b>	5 <b>0.9</b>	4 1.0	0 <b>0.0</b>	0 <b>0.0</b>	34 <b>0.8</b>	7
Trisomy 13	14 <b>0.4</b>	4 <b>0.</b> 7	5 1.3	0 <b>0.0</b>	0 <b>0.0</b>	23 <b>0.5</b>	
Trisomy 18	37 1.2	9 <b>1.6</b>	5 1.3	1 <b>1.0</b>	0 <b>0.0</b>	53 1.2	
Ventricular septal defect	1336 41.9	137 <b>24.4</b>	149 <b>38.6</b>	40 41.2	1 12.8	1688 <b>39.1</b>	8
Total Live Births	318802	56253	38559	9700	780	431306	
<b>Total Male Live Births</b>	163503	28470	19664	5017	372	220710	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Indiana Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age						
Defect	Less than 35	35 and greater	Total**	Notes		
Down syndrome (Trisomy 21)	298 7. <b>8</b>	217 <b>46.8</b>	515 <b>11.9</b>			
Trisomy 13	17 <b>0.4</b>	6 1.3	23 <b>0.5</b>			
Trisomy 18	31 <b>0.8</b>	21 <b>4.5</b>	53 <b>1.2</b>			
<b>Total Live Births</b>	383803	46415	431306			

<sup>\*\*</sup>Total includes unknown maternal age

- 1.Large increase in the number of probable cases of Atrial Septal Defect and Patent Ductus Arteriosus for 2010; believed to stem from an increased awareness of congenital heart defects among physicians statewide, and a large increase in the number of echocardiograms ordered at less than 6 weeks of age, with no follow-up echo performed after 6 weeks to invalidate/confirm.
- 2. Atrioventricular septal defect: Data does not distinguish BPA code 745.487 (2006-2010).
- 3.Prior to July 2009, all children reported with either hypospadias or epispadias were reviewed for a combined disorder of 'hypospadias/epispadias.' Since that time our system was modified and children are currently reviewed for hypospadius and epispadias separately.
- 4.Indiana utilizes BPA codes to differentiate gastroschisis from omphalocele.
- 5.Data reported for children who were gestational age greater than or equal to 36 weeks at birth and whose PDA was last noted at greater than or equal to 6 weeks of age (2006-2010); Unable to exclude infants of less than 2500 grams birth weight. Large increase in the number of probable cases of Atrial Septal Defect and Patent Ductus Arteriosus for 2010; believed to stem from an increased awareness of congenital heart defects among physicians statewide, and a large increase in the number of echocardiograms ordered at less than 6 weeks of age, with no follow-up echo performed after 6 weeks to invalidate/confirm.
- 6.Transposition of great arteries: Data includes entire coding range of 745.10 745.19 (2006-2010).
- 7.Tricuspid valve atresia and stenosis: Data does not distinguish BPA codes 746.105 or 746.106 (2006-2010).
- 8. Ventricular septal defect: Data does not distinguish BPA code 745.487 (2006-2010); Probable cases included.
- 9.&c9

- -Birth defects rates based on fewer than 20 cases are unstable.
- -Case ascertainment in Indiana is a combination of passive ascertainment by electronic submission of hospital discharge information and active ascertainment through chart auditing of 45 targeted conditions identified through hospital discharge ICD-9-CM codes.
- -Data includes children whose conditions were classified with a status of either 'confirmed' or 'probable' based on the abstracted information.
- -Indiana does not collect or report information on stillbirths or terminations. Data reported is based on livebirths (2006-2010).
- -Report based on data as of 05/24/2013. As additional information is constantly entering the system, updated data for birth years 2007-2010 will be submitted, along with 2011 data, in the next report.

Iowa Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Amniotic bands	17	4	4	0	0	26		
Anencephalus	<b>1.0</b> 47	<b>4.8</b> 3	<b>2.5</b> 7	<b>0.0</b> 2	0.0	1.3 61		
	2.8	3.6	4.3	4.1	0.0	3.1		
Anophthalmia/microphthalmia	32 1.9	4 <b>4.8</b>	7 <b>4.3</b>	2 <b>4.1</b>	1 10.1	46 <b>2.3</b>		
Anotia/microtia	32	1	9	0	0	43		
Aortic valve stenosis	1.9 56	1.2 2	5.5 1	<b>0.0</b> 3	<b>0.0</b> 2	2.2 64		
	3.3	2.4	0.6	6.2	20.1	3.2		
Atrial septal defect	504 <b>30.0</b>	35 <b>42.0</b>	43 <b>26.3</b>	8 16.5	8 <b>80.6</b>	600 <b>30.0</b>		
Atrioventricular septal defect	111	8	13	3	0	135		
(endocardial cushion defect)	<b>6.6</b> 7	<b>9.6</b> 2	<b>8.0</b> 0	<b>6.2</b> 0	<b>0.0</b>	<b>6.8</b> 9		
Biliary atresia	0.4	2.4	0.0	<b>0.0</b>	0.0	0.5		
Bladder exstrophy	4	0	0	0	0	4		
Choanal atresia	<b>0.2</b> 34	<b>0.0</b>	<b>0.0</b> 2	<b>0.0</b> 1	<b>0.0</b>	<b>0.2</b> 38		
	2.0	1.2	1.2	2.1	0.0	1.9		
Cleft lip with and without cleft palate	169 <b>10.1</b>	11 13.2	18 <b>11.0</b>	5 <b>10.3</b>	2 <b>20.1</b>	205 10.3		
Cleft palate without cleft lip	133	2	10	4	1	150		
Coarctation of aorta	7.9 95	2.4 3	<b>6.1</b> 8	<b>8.2</b> 1	<b>10.1</b>	7.5 108		
Coarctation of aorta	5.7	3.6	4.9	2.1	10.1	5.4		
Common truncus	8 <b>0.5</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 2.1	0 <b>0.0</b>	9 <b>0.5</b>		
Congenital cataract	45	1	5	3	1	55		
	2.7	1.2	3.1	6.2	10.1	2.8		
Congenital hip dislocation	87 <b>5.2</b>	3 <b>3.6</b>	9 <b>5.5</b>	5 <b>10.3</b>	0 <b>0.0</b>	104 <b>5.2</b>		
Diaphragmatic hernia	20	1	1	0	0	22		
Down syndrome (Trisomy 21)	<b>1.2</b> 237	1.2 8	<b>0.6</b> 38	<b>0.0</b> 10	<b>0.0</b>	1.1 299		
	14.1	9.6	23.3	20.6	0.0	15.0		
Ebstein anomaly	17 <b>1.0</b>	0 <b>0.0</b>	1 <b>0.6</b>	1 2.1	0 <b>0.0</b>	19 <b>1.0</b>		
Encephalocele	19	0	1	0	0	21		
Epispadias	1.1 8	0.0	<b>0.6</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	1.1 8		
Epispadias	0.5	0.0	0.0	0.0	0.0	0.4		
Esophageal atresia/tracheoesophageal	37	0	3	2	0	42		
fistula Fetus or newborn affected by maternal	2.2 6	0.0	1.8 0	<b>4.1</b> 0	0.0	<b>2.1</b> 7		
alcohol use	0.4	0.0	0.0	0.0	0.0	0.4		
Gastroschisis	77 <b>4.6</b>	6 7.2	13 <b>8.0</b>	3 <b>6.2</b>	3 30.2	102 <b>5.1</b>	1	
Hirschsprung disease (congenital	29	2	3	0	1	35		
megacolon) Hydrocephalus without spina bifida	<b>1.7</b> 193	<b>2.4</b> 11	<b>1.8</b> 19	<b>0.0</b> 7	<b>10.1</b> 0	1.8 234		
	11.5	13.2	11.6	14.4	0.0	11.7		
Hypoplastic left heart syndrome	43 <b>2.6</b>	2 <b>2.4</b>	5 <b>3.1</b>	1 <b>2.</b> 1	0 <b>0.0</b>	51 <b>2.6</b>		
Hypospadias*	458	19	22	7	1	508		
	53.3	44.5	26.5	28.6	19.5	<i>49.7</i>		
Microcephalus	183 <b>10.9</b>	14 <b>16.8</b>	21 <b>12.9</b>	5 <b>10.3</b>	1 <b>10.1</b>	225 11.3		
Obstructive genitourinary defect	490	18	52	15	2	579		
Omphalocele	<b>29.2</b> 46	<b>21.6</b> 3	<i>31.9</i> 2	<b>30.9</b> 1	<b>20.1</b> 0	<b>29.0</b> 53	1	
	2.7	3.6	1.2	2.1	0.0	2.7		
Patent ductus arteriosus	448 <b>26.7</b>	22 <b>26.4</b>	54 <b>33.1</b>	14 <b>28.9</b>	4 40.3	545 <b>27.3</b>	2	

Iowa Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Pulmonary valve atresia and stenosis	207	9	11	7	2	238		
	12.3	10.8	<b>6.</b> 7	14.4	20.1	11.9		
Pulmonary valve atresia	19	1	0	1	0	21		
	1.1	1.2	0.0	2.1	0.0	1.1		
Pyloric stenosis	429	14	40	1	4	489		
	25.6	16.8	24.5	2.1	40.3	24.5		
Rectal and large intestinal atresia/stenosis		6	12	3	0	99		
D 1 41 1 C 14 1 11 1	4.6	7.2	7.4	6.2	0.0	5.0		
Reduction deformity, lower limbs	31 <b>1.8</b>	5 <b>6.0</b>	3 1.8	3 <b>6.2</b>	0 <b>0.0</b>	42 <b>2.1</b>		
Reduction deformity, upper limbs	68	9	1.0	2	0.0	90		
Reduction deformity, upper minos	4.1	10.8	<b>6.</b> 7	4.1	0.0	4.5		
Renal agenesis/hypoplasia	120	5	11	4.1	0.0	142		
Renar agenesis/hypopiasia	7.2	6.0	<b>6.</b> 7	8.2	0.0	7.1		
Spina bifida without anencephalus	70	7	14	1	1	93		
Spina offica without anencepharus	4.2	8.4	8.6	2.1	10.1	<i>4.7</i>		
Tetralogy of Fallot	61	2	6	1	1	72		
reduced of runot	3.6	2.4	3.7	2.1	10.1	3.6		
Total anomalous pulmonary venous return		0	4	0	1	27		
(TAPVR)	1.3	0.0	2.5	0.0	10.1	1.4		
Transposition of great arteries - All	57	2	3	3	0	66		
	3.4	2.4	1.8	6.2	0.0	3.3		
dextro-Transposition of great arteries	49	1	3	3	0	56		
(d-TGA)	2.9	1.2	1.8	6.2	0.0	2.8		
Tricuspid valve atresia and stenosis	43	1	4	0	2	51		
	2.6	1.2	2.5	0.0	20.1	2.6		
Tricuspid valve atresia	14	0	2	0	1	17		
	0.8	0.0	1.2	0.0	10.1	0.9		
Trisomy 13	24	1	4	1	0	33		
	1.4	1.2	2.5	2.1	0.0	1.7		
Trisomy 18	53	6	8	1	0	69		
Y .: 1	3.2	7.2	4.9	2.1	0.0	3.5	2	
Ventricular septal defect	940	38	87	23	8	1098	3	
T A IX: D: 41	56.0	45.6	53.3	47.4	80.6	54.9		
Total Live Births	167743	8326	16325	4851	993	199824		
<b>Total Male Live Births</b>	85932	4271	8306	2444	514	102277		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

Iowa Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

		Age		
Defect	Less than 35	35 and greater	Total**	Notes
Down syndrome (Trisomy 21)	163 <b>9.1</b>	135 <b>62.9</b>	299 <b>15.0</b>	
Trisomy 13	24 1.3	9 <b>4.2</b>	33 1.7	
Trisomy 18	40 2.2	29 <b>13.5</b>	69 <b>3.5</b>	
<b>Total Live Births</b>	178356	21459	199824	

<sup>\*\*</sup>Total includes unknown maternal age

- 1.Use BPA codes to distinguish omphalocele and gastroschisis
  2.Included only if weight greater than or equal to 2500 grams. Did not exclude if gestational less than 36 weeks and was not able to determine if defects last noted greater than or equal to 6 weeks of age
- 3. Probable cases are not included.

Kansas Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Amniotic bands	5	0	2	0	0	7	110005
	0.4	0.0	0.6	0.0	0.0	0.4	
Anencephalus	30 <b>2.1</b>	3 <b>2.2</b>	15 <b>4.6</b>	1 1.8	1 <b>8.6</b>	50 <b>2.5</b>	
Anophthalmia/microphthalmia	1	0	0	0	0	3	
	0.1	0.0	0.0	0.0	0.0	0.2	
Anotia/microtia	2 <b>0.1</b>	0 <b>0.0</b>	6 <b>1.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	8 <b>0.4</b>	
Aortic valve stenosis	1	0.0	1	0.0	0.0	3	
	0.1	0.0	0.3	0.0	0.0	0.2	
Atrial septal defect	168	27	87	5	1	684	
Atrioventricular septal defect	11.8 10	<b>19.5</b>	<b>26.5</b> 3	<b>8.8</b> 0	<b>8.6</b> 0	<b>34.3</b> 17	
(endocardial cushion defect)	0.7	0.7	0.9	0.0	0.0	0.9	
Biliary atresia	1	0	1	0	0	3	
DI 11	0.1	0.0	0.3	0.0	0.0	0.2	
Bladder exstrophy	2 <b>0.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.2</b>	
Choanal atresia	3	0.0	1	0.0	0.0	10	
	0.2	0.0	0.3	0.0	0.0	0.5	
Cleft lip with and without cleft palate	122	5	30	3	1	181	
Cleft palate without cleft lip	<b>8.6</b> 52	<b>3.6</b> 4	<b>9.1</b> 22	<b>5.3</b> 2	<b>8.6</b> 2	<b>9.1</b> 96	
Cleft palate without cleft lip	3.7	2.9	<b>6.</b> 7	3.5	17.2	4.8	
Coarctation of aorta	3	0	3	0	0	20	
	0.2	0.0	0.9	0.0	0.0	1.0	
Common truncus	1 <b>0.1</b>	0 <b>0.0</b>	0	0 <b>0.0</b>	0 <b>0.0</b>	4 <b>0.2</b>	
Congenital cataract	0.1	0.0	<b>0.0</b>	0.0	0.0	3	
	0.0	0.0	0.3	0.0	0.0	0.2	
Congenital hip dislocation	12	0	4	0	0	38	
Diaphragmatic hernia	<b>0.8</b> 11	<b>0.0</b>	<b>1.2</b> 7	<b>0.0</b> 1	<b>0.0</b> 0	1.9 26	
Diapinagmatic nerma	0.8	<b>0.</b> 7	2.1	1.8	0.0	1.3	
Down syndrome (Trisomy 21)	130	6	36	5	0	203	
	9.2	4.3	11.0	8.8	0.0	10.2	
Ebstein anomaly	0 <b>0.0</b>	0	1 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.2</b>	
Encephalocele	5	<b>0.0</b> 0	2	0.0	0.0	8	
Encepharoceie	0.4	0.0	0.6	0.0	0.0	0.4	
Epispadias	0	1	2	0	0	3	
Esophageal atresia/tracheoesophageal	0.0	0.7	<b>0.6</b> 3	0.0	0.0	0.2	
fistula	9 <b>0.6</b>	0 <b>0.0</b>	3 <b>0.9</b>	0 <b>0.0</b>	0.0	18 <b>0.9</b>	
Fetus or newborn affected by maternal	4	0	0	0	0	7	
alcohol use	0.3	0.0	0.0	0.0	0.0	0.4	
Gastroschisis	61	4	9	1	0	99	
Hirschsprung disease (congenital	<b>4.3</b> 5	<b>2.9</b> 0	2.7 4	1.8 0	0.0	<b>5.0</b> 18	
megacolon)	0.4	0.0	1.2	0.0	0.0	0.9	
Hydrocephalus without spina bifida	34	5	9	0	0	75	
H 1 ( 101 )	2.4	3.6	2.7	0.0	0.0	3.8	
Hypoplastic left heart syndrome	10 <b>0.</b> 7	0 <b>0.0</b>	5 <b>1.5</b>	1 <b>1.8</b>	0 <b>0.0</b>	22 <b>1.1</b>	
Hypospadias*	131	14	21	2	1	244	
	18.0	20.0	12.6	<b>6.</b> 7	17.2	23.9	
Microcephalus	4	2	9	0	0	27	
Obstructive genitourinary defect	<b>0.3</b> 63	1.4 6	<b>2.7</b> 34	<b>0.0</b> 5	0.0	<b>1.4</b> 192	
Josh denve gennourmary defect	4.4	4.3	10.4	<b>8.8</b>	0.0	9.6	

Kansas Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Omphalocele	24	2	4	2	0	37	
1	1.7	1.4	1.2	3.5	0.0	1.9	
Patent ductus arteriosus	64	10	40	1	1	133	1
	4.5	7.2	12.2	1.8	8.6	<b>6.</b> 7	
Pulmonary valve atresia and stenosis	15	3	3	0	0	38	
·	1.1	2.2	0.9	0.0	0.0	1.9	
Pyloric stenosis	41	1	19	0	1	119	
	2.9	0.7	5.8	0.0	8.6	6.0	
Rectal and large intestinal atresia/stenosis	5	2	8	2	0	28	
C	0.4	1.4	2.4	3.5	0.0	1.4	
Reduction deformity, lower limbs	11	0	1	1	0	21	
• *	0.8	0.0	0.3	1.8	0.0	1.1	
Reduction deformity, upper limbs	8	1	5	1	0	22	
37 11	0.6	0.7	1.5	1.8	0.0	1.1	
Renal agenesis/hypoplasia	11	2	5	0	0	26	
21 1	0.8	1.4	1.5	0.0	0.0	1.3	
Spina bifida without anencephalus	31	2	12	0	0	64	
•	2.2	1.4	3.7	0.0	0.0	3.2	
Tetralogy of Fallot	9	0	4	0	0	20	
6.5	0.6	0.0	1.2	0.0	0.0	1.0	
Total anomalous pulmonary venous return	1	0	0	0	0	4	
(TAPVR)	0.1	0.0	0.0	0.0	0.0	0.2	
Transposition of great arteries - All	15	1	6	0	0	32	
	1.1	0.7	1.8	0.0	0.0	1.6	
Tricuspid valve atresia and stenosis	1	1	2	0	0	4	
1	0.1	0.7	0.6	0.0	0.0	0.2	
Trisomy 13	4	0	2	2	0	13	
,	0.3	0.0	0.6	3.5	0.0	0.7	
Trisomy 18	14	1	9	0	0	26	
·	1.0	0.7	2.7	0.0	0.0	1.3	
Ventricular septal defect	76	6	56	1	1	271	
ī	5.4	4.3	17.1	1.8	8.6	13.6	
<b>Total Live Births</b>	141995	13881	32825	5709	1164	199493	
<b>Total Male Live Births</b>	72650	7017	16730	2973	580	101955	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

**Kansas** Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)						
Defect	Less than 35	35+	Total	Notes		
Down syndrome (Trisomy 21)	112	76	203			
	6.3	36.2	10.2			
Trisomy 13	6	3	13			
	0.3	1.4	0.7			
Trisomy 18	13	12	26			
	<b>0.</b> 7	5.7	1.3			
Total Live Births	178484	20991	199493			

<sup>\*\*</sup>Total includes unknown maternal age

1.Includes only birth weight >=2500g or gestational age >=36 weeks; unable to select defect last noted at >=6 wks of age.

- General comments
  -A passive system; all are probable cases; Includes in-state resident births only.
  -Aniridia had zero cases reported
- -Kansas does not formally provide CCHD screening. No data is available for pulmonary valve atresia, dextro-Transposition of great arteries (d-TGA) or Tricuspid valve atresia.

Kentucky Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Anencephalus	40	4	5	0	0	50	11000
	1.7	1.5	3.5	0.0	0.0	1.8	
Aniridia	2 <b>0.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.1</b>	
Anophthalmia/microphthalmia	10	3	0	0	0	13	
Anotia/microtia	<b>0.4</b> 8	<b>1.2</b>	<b>0.0</b> 3	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.5</b> 13	
Anotta/interotta	0.3	0.4	2.1	2.6	0.0	0.5	
Aortic valve stenosis	30	3	1 <b>0.</b> 7	1 <b>2.6</b>	0 <b>0.0</b>	36 <b>1.3</b>	
Atrial septal defect	1.3 3785	<b>1.2</b> 848	<b>0.</b> / 191	<b>2.0</b> 48	5	5040	1
	159.5	326.1	132.7	122.8	148.4	177.3	
Atrioventricular septal defect (endocardial cushion defect)	61 <b>2.6</b>	8 3.1	3 <b>2.1</b>	1 <b>2.6</b>	0 <b>0.0</b>	75 <b>2.6</b>	
Biliary atresia	10	1	2	0	0	13	
DI 11 ( 1	0.4	0.4	1.4	0.0	0.0	0.5	
Bladder exstrophy	5 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	5 <b>0.2</b>	
Choanal atresia	25	2	1	0	0	29	
Cleft lip with and without cleft palate	1.1 236	<b>0.8</b> 19	<b>0.</b> 7 13	<b>0.0</b> 1	0.0	1.0 284	
Cleft lip with and without cleft parate	9.9	7.3	9.0	2.6	0.0	10.0	
Cleft palate without cleft lip	103	7	1	2	0	117	
Coarctation of aorta	<b>4.3</b> 117	2.7 11	<b>0.</b> 7	<b>5.1</b>	0.0	<b>4.1</b> 134	
Confidence of north	6.2	5.3	3.5	3.3	0.0	5.9	
Common truncus	12 <b>0.6</b>	1 <b>0.5</b>	1 <b>0.9</b>	0 <b>0.0</b>	0 <b>0.0</b>	15 <b>0.</b> 7	
Congenital cataract	15	1	2	0.0	0.0	18	
	0.6	0.4	1.4	0.0	0.0	0.6	
Congenital hip dislocation	143 <b>6.0</b>	6 <b>2.3</b>	5 <b>3.5</b>	1 <b>2.6</b>	0 <b>0.0</b>	164 <b>5.8</b>	
Diaphragmatic hernia	59	7	1	0	0	71	
Down syndrome (Trisomy 21)	<b>3.1</b> 248	<b>3.4</b> 28	<b>0.9</b> 17	<b>0.0</b> 4	<b>0.0</b>	<b>3.1</b> 303	
Down syndrome (11180my 21)	10.5	10.8	11.8	10.2	29.7	10.7	
Ebstein anomaly	14	0	0	0	0	14	
Encephalocele	<b>0.6</b> 15	<b>0.0</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.5</b> 17	
_	0.6	0.4	0.0	0.0	0.0	0.6	
Epispadias	16 <b>1.1</b>	3 <b>2.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	19 <b>1.1</b>	
Esophageal atresia/tracheoesophageal	46	5	3	1	0	57	
fistula	1.9	1.9	2.1	2.6	0.0	2.0	
Fetus or newborn affected by maternal alcohol use	19 <b>0.8</b>	15 <b>5.8</b>	2 1.4	2.6	1 29.7	47 <b>1.</b> 7	
Gastroschisis	83	5	6	0	0	103	
Hirschsprung disease (congenital	<b>3.5</b> 45	<b>1.9</b>	<b>4.2</b>	<b>0.0</b> 3	0.0	<b>3.6</b> 63	
megacolon)	1.9	4.2	0.7	7. <i>7</i>	0.0	2.2	
Hydrocephalus without spina bifida	119	9	3	1	1	133	
Hypoplastic left heart syndrome	<b>5.0</b> 60	3.5 8	2.1 4	<b>2.6</b> 0	<b>29.</b> 7 0	<b>4.7</b> 77	
	2.5	3.1	2.8	0.0	0.0	2.7	
Hypospadias*	933 <b>76.</b> 7	108 <b>81.</b> 7	27 <b>37.0</b>	5 <b>24.8</b>	1 <b>58.1</b>	1092 <b>75.0</b>	
Microcephalus	65	14	3	0	0	83	
	2.7	5.4	2.1	0.0	0.0	2.9	
Obstructive genitourinary defect	447 <b>18.8</b>	40 <b>15.4</b>	32 <b>22.2</b>	7 <b>17.9</b>	0 <b>0.0</b>	543 <b>19.1</b>	
Omphalocele	25	6	2	0	0	35	
Patent ductus arteriosus	<b>1.1</b> 1716	<b>2.3</b> 354	<b>1.4</b> 97	<b>0.0</b> 15	<b>0.0</b> 3	<b>1.2</b> 2220	
i atent ductus arteriosus	72.3	334 136.1	67.4	38.4	3 <b>89.0</b>	78.1	

Kentucky Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal Ra	ace/Ethnicity				
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Pulmonary valve atresia and stenosis	171	19	7	2	0	202	
	7.2	7.3	4.9	5.1	0.0	7.1	
Pulmonary valve atresia	30	3	1	0	0	37	
	6.7	6.4	3.6	0.0	0.0	6.8	
Pyloric stenosis	736	41	16	3	1	806	
D (1 11 ) (1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	31.0	15.8	11.1	7.7	29.7	28.4	
Rectal and large intestinal atresia/stenosis		16	5	3	0	157	
D - dti d-fit 1 1ib	<i>5.3</i> 33	6.2	3.5	7.7	0.0	<b>5.5</b> 41	
Reduction deformity, lower limbs	33 1.4	2 <b>0.8</b>	2 1.4	0 <b>0.0</b>	0 <b>0.0</b>	41 <b>1.4</b>	
Reduction deformity, upper limbs	38	3	1.4	<b>0.0</b>	1	1.4 44	
Reduction deformity, upper minos	1.6	1.2	<b>0.</b> 7	2.6	29.7	1.5	
Renal agenesis/hypoplasia	105	10	5	1	0	123	
Kenai agenesis/nypopiasia	4.4	3.8	3.5	2.6	0.0	4.3	
Spina bifida without anencephalus	87	9	2	0	0	100	
Spina offica without anoneopharas	3.7	3.5	1.4	0.0	0.0	3.5	
Tetralogy of Fallot	82	11	2	1	0	98	
	3.5	4.2	1.4	2.6	0.0	3.4	
Total anomalous pulmonary venous return	19	1	1	0	0	11	
(TAPVR)	1.0	1.0	1.7	0.0	0.0	1.0	
Transposition of great arteries - All	92	9	5	1	0	110	
	3.9	3.5	3.5	2.6	0.0	3.9	
dextro-Transposition of great arteries	5	1	0	0	0	7	
(d-TGA)	1.1	2.1	0.0	0.0	0.0	1.3	
Tricuspid valve atresia and stenosis	24	3	1	0	0	29	
	1.0	1.2	<b>0.</b> 7	0.0	0.0	1.0	
Tricuspid valve atresia	5	1	0	0	0	7	
	1.1	2.1	0.0	0.0	0.0	1.3	
Trisomy 13	18	2	3	0	0	25	
T. 10	0.8	0.8	2.1	0.0	0.0	0.9	
Trisomy 18	40	1	3	0	0	45	
Vantriaular cantal defeat	1.7 969	<b>0.4</b> 125	2.1 61	<b>0.0</b> 14	0.0	1.6 1220	1
Ventricular septal defect	969 <b>40.8</b>	125 <b>48.1</b>	42.4	35.8	1 29.7	1220 <b>42.9</b>	1
<b>Total Live Births</b>	237305	26004	14398	3910	337	284258	
I Otal Live Dil tils	431303	40004	17370	3710	331	404430	
<b>Total Male Live Births</b>	121648	13226	7295	2020	172	145540	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

Kentucky Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age						
Defect	Less than 35	35 and greater	Total**	Notes		
Down syndrome (Trisomy 21)	163 <b>6.4</b>	131 <b>47.9</b>	303 <b>10.7</b>			
Trisomy 13	21 <b>0.8</b>	3 1.1	25 <b>0.9</b>			
Trisomy 18	13 <b>0.5</b>	20 7.3	45 <b>1.6</b>			
<b>Total Live Births</b>	256276	27360	284258			

<sup>\*\*</sup>Total includes unknown maternal age

1.Probable cases are included

Louisiana Birth Defects Counts and Prevalence 2006-2008 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Amniotic bands	8	6	<5	0	0	15	Tioles	
Anencephalus	1.1 6	<i>1.1</i> 8	0	<b>0.0</b> 0	<b>0.0</b> 0	<b>1.1</b> 14		
Anencepharus	0.8	1.5	0.0	0.0	0.0	1.0		
Aniridia	0 <b>0.0</b>	<5	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	<5	1	
Anophthalmia/microphthalmia	8	<5	0	0	0	12		
Anotia/microtia	1.1 8	0	<b>0.0</b> <5	<b>0.0</b> 0	0.0	<b>0.9</b> 11		
	1.1	0.0		0.0	0.0	0.8		
Aortic valve stenosis	17 <b>2.4</b>	9 <b>1.6</b>	0 <b>0.0</b>	<5 •	0 <b>0.0</b>	27 <b>2.0</b>		
Atrial septal defect	450	324	36	16 <b>63.4</b>	5	833		
Atrioventricular septal defect	<b>63.5</b> 53	<b>59.2</b> 25	<b>51.5</b> <5	5	<b>85.0</b> 0	<b>61.2</b> 85		
(endocardial cushion defect)	7.5 10	<b>4.6</b> 8	· <5	19.8 <5	0.0	<b>6.2</b> 21		
Biliary atresia	1.4	8 1.5	•	•	0 <b>0.0</b>	1.5		
Bladder exstrophy	<5	<5	0 <b>0.0</b>	0 <b>0.0</b>	<5	8 <b>0.6</b>		
Choanal atresia	14	6	<b>&lt;</b> 5	0	0	22		
Cleft lip with and without cleft palate	<b>2.0</b> 59	1.1 36	. 11	<b>0.0</b> <5	<b>0.0</b> <5	<b>1.6</b> 109		
	8.3	<b>6.6</b>	15.7			8.0		
Cleft palate without cleft lip	63 <b>8.9</b>	30 <b>5.5</b>	6 <b>8.6</b>	<5	0 <b>0.0</b>	100 7.3		
Coarctation of aorta	31	24	<5	<5	0	59		
Common truncus	<b>4.4</b> 11	<b>4.4</b> <5	0	<5	0.0	<b>4.3</b> 16		
	1.6		0.0		0.0	1.2		
Congenital cataract	11 <b>1.6</b>	8 1.5	<5	0 <b>0.0</b>	0 <b>0.0</b>	20 1.5		
Congenital hip dislocation	55	19	<5	<5	<5	80		
Diaphragmatic hernia	7.8 20	<b>3.5</b> 10	5	0	0	<b>5.9</b> 35		
	2.8	1.8	7.2	0.0	0.0	2.6		
Down syndrome (Trisomy 21)	106 <b>15.0</b>	54 <b>9.9</b>	9 <b>12.9</b>	8 <b>31.</b> 7	<5	178 <b>13.1</b>		
Ebstein anomaly	7	5	<5	0	0	13		
Encephalocele	1.0 5	<b>0.9</b> 8	<5	<b>0.0</b> 0	0.0	1.0 14		
•	0.7	1.5		<b>0.0</b> 0	<b>0.0</b>	1.0		
Epispadias	10 <b>1.4</b>	7 <b>1.3</b>	0 <b>0.0</b>	<b>0.0</b>	0.0	17 <b>1.2</b>		
Esophageal atresia/tracheoesophageal fistula	16 <b>2.3</b>	10 <b>1.8</b>	<5	<5	0 <b>0.0</b>	29 <b>2.1</b>		
Fetus or newborn affected by maternal	9	13	· <5	0	<5	24		
alcohol use Gastroschisis	<b>1.3</b> 47	<b>2.4</b> 21	0	<b>0.0</b> 0	0	1.8 68		
	6.6	3.8	0.0	0.0	0.0	5.0		
Hirschsprung disease (congenital megacolon)	20 <b>2.8</b>	21 <b>3.8</b>	<5	0 <b>0.0</b>	0 <b>0.0</b>	42 <b>3.1</b>		
Hydrocephalus without spina bifida	32	35	5	<5	<5	76		
Hypoplastic left heart syndrome	<b>4.5</b> 11	<b>6.4</b> 10	<b>7.2</b> <5	0	<5	<b>5.6</b> 24		
	1.6	1.8		0.0		1.8		
Hypospadias*	283 <b>78.0</b>	161 <b>57.8</b>	9 <b>25.3</b>	<5	<5	459 <b>66.0</b>		
Microcephalus	56	88	5	<5	0	151		
Obstructive genitourinary defect	7.9 202	16.1 123	7.2 16	<5	<b>0.0</b> <5	11.1 348		
	28.5	22.5	22.9			25.6		
Omphalocele	9 <b>1.3</b>	15 2.7	<5	0 <b>0.0</b>	<5	26 1.9		

Louisiana Birth Defects Counts and Prevalence 2006-2008 (Prevalence per 10,000 Live Births)

		Maternal Ra	ce/Ethnicity				
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Patent ductus arteriosus	293	175	18	8	<5	495	2
	41.3	32.0	25.8	31.7		36.3	
Pulmonary valve atresia and stenosis	60	46	<5	<5	0	112	
	8.5	8.4	•	•	0.0	8.2	
Pulmonary valve atresia	12	5	0	0	0	17	
	1.7	0.9	0.0	0.0	0.0	1.2	
Pyloric stenosis	112	36	10	<5	<5	163	
D (1 11 ) (1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	15.8	6.6	14.3	•	•	12.0	
Rectal and large intestinal atresia/stenosis		23	<5	<5	<5	62	
D 1 C 1 C 2 1 1 1 1	4.8	4.2	•	•	•	4.6	
Reduction deformity, lower limbs	11	12	<5	0 <b>0.0</b>	0 <b>0.0</b>	24	
D 1 (1 1 C 1)	1.6	2.2	•			1.8	
Reduction deformity, upper limbs	15 <b>2.1</b>	15	<5	0 <b>0.0</b>	0 <b>0.0</b>	32 <b>2.3</b>	
D 1 ' // 1 '	38	2.7 28	· <5				
Renal agenesis/hypoplasia			<>>	0	0	67	
Color bif to soldbook and a sold blood	5.4 26	<b>5.1</b> 11	<5	<b>0.0</b> <5	0.0	<b>4.9</b> 40	
Spina bifida without anencephalus	3.7	2.0	<b>&gt;</b>	< <u>&gt;</u>	<b>0</b> .0	2.9	
Tetralogy of Fallot	31	2.0	· <5	0	0.0	54	
renalogy of Fanot	4.4	3.8	<b>\</b> 3	<b>0.0</b>	0.0	4. <b>0</b>	
Transposition of great arteries - All	32	15	· <5	<5	<5	50	
Transposition of great afteries - An	4.5	2.7	<b>\</b>	<b>\</b>	<b>\</b>	3.7	
dextro-Transposition of great arteries	29	14	· <5	· <5	· <5	46	
(d-TGA)	4.1	2.6	<b>\</b> 3	<b>\</b> 3	<b>\</b> 3	3.4	
Tricuspid valve atresia and stenosis	<5	8	· <5	<5	0	13	
Theuspia varve attesta and stenosis	~	1.5	~	<b>~</b> 5	0.0	1.0	
Tricuspid valve atresia	· <5	6	· <5	· <5	0.0	11	
Theaspia varve arresia		ĭ.1			0.0	0.8	
Trisomy 13	<5	<5	<5	0	0	9	
11.50.11.5				0.0	0.0	0.7	
Trisomy 18	15	5	· <5	<5	0.0	24	
11100111, 10	2.1	0.9			0.0	1.8	
Ventricular septal defect	438	241	30	11	<5	724	
The section of the se	61.8	44.0	42.9	43.6		53.2	
<b>Total Live Births</b>	70886	54755	6989	2525	588	136201	
<b>Total Male Live Births</b>	36271	27854	3563	1299	284	69506	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

# Louisiana Trisomy Counts and Prevalence by Maternal Age 2006-2008 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35 years old	35 years old or older	Total	Notes			
Down syndrome (Trisomy 21)	99	79	178				
· · · · · ·	8.0	61.1	13.1				
Trisomy 13	7	<5	9				
•	0.6	•	<b>0.</b> 7				
Trisomy 18	16	8	24				
	1.3	6.2	1.8				
Total Live Births	123257	12932	136201				

<sup>\*\*</sup>Total includes unknown maternal age

#### Notes

1. Aniridia only reported for 2008

2.Includes only if weight =>2500 grams or gestational age >=36 wks, however, unable to define if defect lasted at >= 6 wks of age

- -2006 birth defects data include only live births to Louisiana residents at birth that occurred in Greater New Orleans, Baton Rouge, Lake Charles and Shreveport areas.
- -2007 birth defects data include only live births to Louisiana residents at birth that occurred in Greater New Orleans, Baton Rouge, Lafayette, Lake Charles, Mandeville, and Shreveport areas
- -2008 birth defects data are provisional and include only live births to Louisiana residents that occurred in Greater New Orleans, Baton Rouge, Lafayette, Lake Charles, Mandeville, and Shreveport
- -2009 birth defects data are not provided because most of records have not been reviewed
- -All probable cases are included  $\bar{\ }$
- -CDC/BPA codes are used to define the birth defects
- -Louisiana is an active surveillance state that began identifying births in 2005. Birth defects surveillance has not been conducted among terminations and stillbirths yet

Maine Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Anencephalus	8	0	0	0	0	9		
	1.3	0.0	0.0	0.0	0.0	1.4		
Cleft lip with and without cleft palate	49	0	0	1	1	53		
	7.9	0.0	0.0	9.0	17.8	8.0		
Cleft palate without cleft lip	44	0	0	0	0	44		
	7.1	0.0	0.0	0.0	0.0	6.6		
Coarctation of aorta	30 <b>4.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	30 <b>4.5</b>		
Common truncus	7	0.0	0.0	0.0	0.0	7		
Common duncus	1.1	0.0	0.0	0.0	0.0	1.1		
Down syndrome (Trisomy 21)	71	1	3	0.0	1	81		
Down syndrome (11130my 21)	11.5	5.8	29.3	0.0	17.8	12.2		
Encephalocele	2	0	1	0	0	3		
zneephwioeete	0.3	0.0	9.8	0.0	0.0	0.5		
Gastroschisis	39	0	0	2	0	41	1	
	6.3	0.0	0.0	18.1	0.0	6.2		
Hypoplastic left heart syndrome	18	0	1	0	0	21		
	2.9	0.0	9.8	0.0	0.0	3.2		
Hypospadias*	116	5	2	1	1	125	2	
	62.6	86.1	64.3	30.6	54.3	62.5		
Omphalocele	15	0	0	0	0	15	3	
	2.4	0.0	0.0	0.0	0.0	2.3		
Pulmonary valve atresia	8	0	0	0	0	8		
	0.6	0.0	0.0	0.0	0.0	0.6	2	
Reduction deformity, lower limbs	2 <b>0.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.5</b>	2	
Daduation deformity, unner limbs	2	0.0	0.0	0.0	1	3	2	
Reduction deformity, upper limbs	0.6	0.0	0.0	<b>0.0</b>	28.3	<b>0.8</b>	Z	
Spina bifida without anencephalus	22	1	0.0	0.0	0	23		
Spina offica without ancheepharus	3.5	5.8	0.0	0.0	0.0	3.5		
Tetralogy of Fallot	22	0	1	0.0	0.0	23	4	
Totalogy of Famor	3.5	0.0	9.8	0.0	0.0	3.5	•	
Transposition of great arteries - All	30	0	0	0	1	32		
	4.8	0.0	0.0	0.0	17.8	4.8		
dextro-Transposition of great arteries	20	0	0	0	0	21		
(d-TGA)	3.2	0.0	0.0	0.0	0.0	3.2		
Tricuspid valve atresia and stenosis	5	0	0	0	0	5		
	0.8	0.0	0.0	0.0	0.0	0.8		
Total Live Births	61985	1724	1024	1108	561	66605		
Total Male Live Births (2008-2010)	18523	581	311	327	184	19995		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

# Maine

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35	35+	Total	Notes			
Down syndrome (Trisomy 21)	49 <b>8.</b> 5	32 <b>34.8</b>	81 <b>12.2</b>				
<b>Total Live Births</b>	57422	9183	66605				

<sup>\*\*</sup>Total includes unknown maternal age

# Notes

- 1. Gastroschisis is coded 756.73. Cases are also abstracted to determine diagnosis 2. Surveillance for this condition began with 2008 births 3. Omphalocele is coded 756.72. Cases are also abstracted to determine diagnosis

- 4.Includes pulmonary atresia with septal defect

- **General comments**-Casefinding is limited to babies born in Maine to Maine residents.
- -Casefinding is limited to birth defects identified within the first year of life.

Maryland Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Amniotic bands	2	2	1	0	0	5		
Anencephalus	<b>0.3</b> 59	<b>0.4</b> 21	<b>0.5</b>	<b>0.0</b> 2	<b>0.0</b>	<b>0.3</b> 100		
	3.4	1.6	1.8	0.8	0.0	2.6		
Anophthalmia/microphthalmia	2 <b>0.1</b>	7 <b>0.5</b>	1 <b>0.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	10 <b>0.3</b>		
Anotia/microtia	9	4	7	2	0.0	22		
	0.5	0.3	1.4	0.8	0.0	0.6		
Aortic valve stenosis	3 <b>0.3</b>	0 <b>0.0</b>	1 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 0.2		
Atrial septal defect	27	26	8	1	0	62		
	1.5	2.0	1.6	0.4	0.0	1.6		
Atrioventricular septal defect (endocardial cushion defect)	21 <b>1.5</b>	18 1.7	3 <b>0.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	42 <b>1.4</b>		
Biliary atresia	0	2	0	0	0	2		
DI II	0.0	0.4	0.0	0.0	0.0	0.1		
Bladder exstrophy	10 <b>0.6</b>	1 <b>0.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	12 <b>0.3</b>		
Choanal atresia	1	2	4	0	0	7		
	0.1	0.2	0.8	0.0	0.0	0.2		
Cleft lip with and without cleft palate	160 <b>9.1</b>	57 <b>4.5</b>	51 <b>10.0</b>	14 <b>5.4</b>	0 <b>0.0</b>	286 7.5		
Cleft palate without cleft lip	83	25	9	3	0	123		
	4.7	2.0	1.8	1.2	0.0	3.2		
Coarctation of aorta	12 <b>0.8</b>	6 <b>0.6</b>	0 <b>0.0</b>	2 1.0	0 <b>0.0</b>	20 <b>0.6</b>		
Common truncus	1	1	0	0	0	2		
	0.1	0.2	0.0	0.0	0.0	0.1		
Congenital cataract	3 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.1</b>		
Congenital hip dislocation	31	5	7	1	0	45		
Diambro amatia harria	1.8 28	<b>0.4</b> 14	6	<b>0.4</b> 2	0.0	1.2 50		
Diaphragmatic hernia	1.6	1.1	1.2	0.8	0.0	1.3		
Down syndrome (Trisomy 21)	199	112	45	26	1	401		
Ebstein anomaly	11.3 7	<b>8.8</b> 0	0	1 <b>0.0</b> 0	12.3 0	1 <b>0.5</b>		
Eostem anomary	0.5	0.0	0.0	0.0	0.0	0.2		
Encephalocele	10	5	1	0	0	17		
Epispadias	<b>0.6</b> 5	<b>0.4</b>	<b>0.2</b> 2	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.4</b> 9		
Epispaulas	0.4	0.1	0.5	0.5	0.0	0.3		
Esophageal atresia/tracheoesophageal	31	20	7	1	0	61		
fistula Gastroschisis	<b>1.8</b> 96	<b>1.6</b> 64	1.4 22	<b>0.4</b> 7	0.0	<b>1.6</b> 196	1	
	5.5	5.0	4.3	2.7	0.0	5.1	1	
Hirschsprung disease (congenital	4	3	0	0	0	7		
megacolon) Hydrocephalus without spina bifida	<b>0.4</b> 70	<b>0.4</b> 46	<b>0.0</b>	<b>0.0</b> 5	0.0	<b>0.3</b> 135		
	4.0	3.6	2.2	1.9	0.0	3.5		
Hypoplastic left heart syndrome	20	8	0	4	0	33		
Hypospadias*	1.4 440	<b>0.8</b> 246	<b>0.0</b> 51	1.9 29	0.0	<b>1.1</b> 781		
Trypospadius	48.6	38.1	19.6	21.5		40.1		
Microcephalus	5	8	6	1	0	20		
Obstructive genitourinary defect	<b>0.3</b> 12	<b>0.6</b> 4	1.2 0	<b>0.4</b> 1	0.0	<b>0.5</b> 17		
	0.9	0.4	0.0	0.5	0.0	0.6		
Patent ductus arteriosus	17	16	4	1	0	38		
Pulmonary valve atresia and stenosis	1.0 5	1.3 5	<b>0.8</b>	<b>0.4</b> 2	0.0	1.0 12		
	0.5	0.6	0.0	1.3	0.0	0.5		
Pulmonary valve atresia	3	1	0	0	0	4		
	0.4	0.2	0.0	0.0	0.0	0.3		

Maryland Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Pyloric stenosis	1	0	0	0	0	1	
	0.3	0.0	0.0	0.0	0.0	0.1	
Rectal and large intestinal atresia/stenosis		23	4	3	0	59	
	1.6	1.8	0.8	1.2	0.0	1.5	
Reduction deformity, lower limbs	32	27	5	1	0	67	
	1.8	2.1	1.0	0.4	0.0	1.8	
Reduction deformity, upper limbs	36	33	14	3	0	88	
	2.0	2.6	2.7	1.2	0.0	2.3	
Renal agenesis/hypoplasia	49	35	4	6	0	98	
0: 1:01 :4	2.8	2.7	0.8	2.3	0.0	2.6	
Spina bifida without anencephalus	64	25	13	5	0	109	
T 1 CF II 1	3.6	2.0	2.6	1.9	0.0	2.9	
Tetralogy of Fallot	21 1.2	19	1 <b>0.2</b>	5	0 <b>0.0</b>	46 1.2	
T	1.2 17	1.5		1.9		43	
Transposition of great arteries - All	1.0	14 <b>1.1</b>	6 1.2	5 <b>1.9</b>	0 <b>0.0</b>	1.1	
dextro-Transposition of great arteries	7	5	4	1.9	0.0	1.1	
(d-TGA)	0.5	0.5	1.0	0.5	0.0	0.6	
Tricuspid valve atresia and stenosis	3	1	0	1	0.0	5	
Thouspid varve alresta and stenosis	<b>0.4</b>	0.2	0.0	1.0	0.0	<b>0.3</b>	
Tricuspid valve atresia	3	1	0.0	1.0	0.0	5	
Tricuspia varve atresta	0.4	0.2	0.0	1.0	0.0	0.3	
Trisomy 13	21	13	3	2	0.0	40	
Trisonly 15	1.2	1.0	0.6	0.8	0.0	1.0	
Trisomy 18	59	21	15	6	0.0	108	
Trisonity 10	3.4	1.6	2.9	2.3	0.0	2.8	
Ventricular septal defect	36	29	6	5	0.0	76	
sepun aeree	2.5	2.8	1.4	2.5	0.0	2.5	
<b>Total Live Births</b>	176074	127596	50963	25957	815	381537	
<b>Total Male Live Births</b>	90449	64557	26052	13464		194978	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

# Maryland Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age						
Defect	Less than 35	35 and greater	Total**	Notes		
Down syndrome (Trisomy 21)	190 <b>6.1</b>	209 <b>29.9</b>	401 <b>10.5</b>			
Trisomy 13	21 <b>0.</b> 7	19 <b>2.</b> 7	40 <b>1.0</b>			
Trisomy 18	48 <b>1.5</b>	59 <b>8.4</b>	108 <b>2.8</b>			
<b>Total Live Births</b>	311496	70003	381537			

<sup>\*\*</sup>Total includes unknown maternal age

#### Notes

1. The data reported for gastroschisis is from ICD9 code 756.79 (Abdominal Wall Defect).

- -Age cutoff for stillbirths and terminations is 20 weeks.
- -All data is based on hospital reporting through a passive collection system. Data obtained from Vital Statistics does not provide specific diagnosis for validation.
- -Data for CCHD is based on hospital reporting and can not be validated through Vital Statistics as there is no requirement to specify the cardiac defect on the birth certificate.
- -Male births for American Indian or Alaska Native not available separate from total.
- -Maryland Vital Statistics do not have a separate race category for Other/Unknown and because HISPANIC category includes all births to mothers of Hispanic origin of any race, this leads to totals not adding up to the total number of births. For 2009 and 2010 the racial categories added up to more than the total number of births so 'Others/Unknowns' could be identified. For 2006 through 2008 we categorized the difference as 'Other/Unknown'.
- -The total number of births data was received from Vital Statistics. HISPANIC category includes all births to mothers of Hispanic origin of any race.
- -Total male live births indicates total live male births in the state of Maryland which includes races categorized as 'other' or American Indian or Alaska Native.

# Massachusetts Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Amniotic bands	22 <b>0.9</b>	7 <b>2.1</b>	8 1.5	0 <b>0.0</b>	0 <b>0.0</b>	37 <b>1.0</b>	
Anencephalus	11	2	4	2	0	21	
Aniridia	<b>0.4</b> 2	<b>0.6</b> 0	<b>0.7</b>	<b>0.7</b> 1	<b>0.0</b> 0	<b>0.6</b> 4	
	0.1	0.0	0.2	0.3	0.0	0.1	
Anophthalmia/microphthalmia	25 <b>1.0</b>	11 <b>3.3</b>	12 2.2	2 <b>0.</b> 7	0 <b>0.0</b>	50 <b>1.3</b>	
Anotia/microtia	41 <b>1.6</b>	3 <b>0.9</b>	14 <b>2.6</b>	10 <b>3.5</b>	0 <b>0.0</b>	69 <b>1.8</b>	
Aortic valve stenosis	45	7	7	1	0	61	
Atrial septal defect	1.8 499	2.1 80	1.3 98	<b>0.3</b> 52	<b>0.0</b> 3	<b>1.6</b> 749	
Atrioventricular septal defect	19.5	24.0	18.1	18.0	38.4	19.7	
(endocardial cushion defect)	132 <b>5.2</b>	23 <b>6.9</b>	16 <b>3.0</b>	6 <b>2.1</b>	0 <b>0.0</b>	183 <b>4.8</b>	
Biliary atresia	12 <b>0.5</b>	1 <b>0.3</b>	4 <b>0.</b> 7	5 1.7	1 12.8	23 <b>0.6</b>	
Bladder exstrophy	4	0	1	0	0	5	1
Choanal atresia	<b>0.2</b> 23	<b>0.0</b>	<b>0.2</b> 5	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.1</b> 30	
	0.9	0.3	0.9	0.0	0.0	0.8	
Cleft lip with and without cleft palate	215 <b>8.4</b>	19 <b>5.</b> 7	39 <b>7.2</b>	25 <b>8.6</b>	0 <b>0.0</b>	303 <b>8.0</b>	
Cleft palate without cleft lip	153 <b>6.0</b>	6 <b>1.8</b>	30 <b>5.6</b>	7 <b>2.4</b>	0 <b>0.0</b>	202 5.3	
Coarctation of aorta	118	11	21	5	1	160	
Common truncus	<b>4.6</b> 13	3.3 1	3.9 2	1.7 0	<b>12.8</b>	<b>4.2</b> 17	
Congenital cataract	<b>0.5</b> 61	<b>0.3</b> 13	<b>0.4</b> 18	<b>0.0</b> 2	<b>12.8</b> 0	<b>0.4</b> 96	
	2.4	3.9	3.3	<b>0.</b> 7	0.0	2.5	
Diaphragmatic hernia	67 <b>2.6</b>	9 <b>2.</b> 7	10 <b>1.9</b>	5 <b>1.</b> 7	1 12.8	100 <b>2.6</b>	
Down syndrome (Trisomy 21)	315	53	75	28	3 38.4	486	
Ebstein anomaly	<b>12.3</b> 11	<b>15.9</b>	13.9 3	<b>9.</b> 7 0	0	12.8 15	
Encephalocele	<b>0.4</b> 4	<b>0.3</b> 0	<b>0.6</b> 3	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.4</b> 8	
	0.2	0.0	0.6	0.0	0.0	0.2	
Esophageal atresia/tracheoesophageal fistula	67 <b>2.6</b>	6 <b>1.8</b>	11 <b>2.0</b>	2 <b>0.</b> 7	1 12.8	88 <b>2.3</b>	
Gastroschisis	70 <b>2.</b> 7	16	33	5	0	132	
Hirschsprung disease (congenital	48	<b>4.8</b> 3	<b>6.1</b> 13	<b>1.7</b> 9	<b>0.0</b>	<b>3.5</b> 76	
megacolon) Hydrocephalus without spina bifida	<b>1.9</b> 66	<b>0.9</b> 24	<b>2.4</b> 24	<b>3.1</b> 3	<b>12.8</b> 0	<b>2.0</b> 122	
	2.6	7.2	4.4	1.0	0.0	3.2	
Hypoplastic left heart syndrome	42 <b>1.6</b>	5 <b>1.5</b>	9 <b>1.7</b>	1 <b>0.3</b>	0 <b>0.0</b>	59 <b>1.6</b>	
Hypospadias*	367 <b>28.0</b>	51 <b>29.9</b>	38 13.7	23 15.4	1 <b>25.4</b>	490 <b>25.1</b>	2
Microcephalus	42	9	12	2	1	66	3
Obstructive genitourinary defect	<b>1.6</b> 383	2.7 48	2.2 102	<b>0.7</b> 43	<b>12.8</b> 0	1.7 590	
	15.0	14.4	18.9	14.9	0.0	15.5	
Omphalocele	28 1.1	9 <b>2.</b> 7	8 1.5	1 <b>0.3</b>	0 <b>0.0</b>	47 1.2	
Patent ductus arteriosus	333 13.0	49	70 <b>13.0</b>	34 11.7	2 25.6	502 13.2	4
Pulmonary valve atresia and stenosis	170	14.7 37	44	17	0	275	
Pulmonary valve atresia	<b>6.7</b> 14	11.1 2	<b>8.1</b> 4	<b>5.9</b> 1	0.0	<b>7.2</b> 22	
	0.5	0.6	<b>0.</b> 7	0.3	0.0	0.6	

# Massachusetts Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

#### Maternal Race/Ethnicity American Asian or Pacific Indian or White Black Islander Alaska Native Non-Hispanic Defect Non-Hispanic Non-Hispanic Hispanic Total\*\* Non-Hispanic Notes Rectal and large intestinal atresia/stenosis 83 20 127 2.7 3.1 12.8 3.3 3.2 3.7 Reduction deformity, lower limbs 29 16 2 0 53 **0.**7 1.1 1.5 3.0 0.0 1.4 Reduction deformity, upper limbs 73 25 110 2.9 1.5 **1.**7 0.0 4.6 2.9 5 Renal agenesis/hypoplasia 6 5 2 0 0 14 0.2 1.5 0.0 0.4 0.0 0.4 Spina bifida without anencephalus 49 14 77 1.9 2.1 1.0 0.0 2.0 2.6 Tetralogy of Fallot 95 20 29 166 16 0 3.7 0.0 6.0 5.4 5.5 4.4 Total anomalous pulmonary venous return 20 34 2 5 0 (TAPVR) 0.6 0.9 0.0 0.9 0.8 2.4 Transposition of great arteries - All 88 119 13 2.7 3.4 2.4 1.4 12.8 3.1 dextro-Transposition of great arteries 76 13 105 3.0 2.1 2.4 1.4 12.8 2.8 Tricuspid valve atresia and stenosis 19 3 2 0 26 0.9 0.7 0.4 0.3 0.0 0.7 Tricuspid valve atresia 18 24 0.6 0.6 0.4 0.0 **0.**7 0.3 Trisomy 13 18 26 0.7 0.9 0.9 0.0 0.0 0.7 Trisomy 18 29 11 15 0 62 1.1 3.3 2.8 1.4 0.0 1.6 Ventricular septal defect 491 69 113 754 6 60 20.7 20.7 0.0 19.8 19.2 20.9 **Total Live Births** 255599 33308 54035 28942 781 380407 130909 17075 14951 393 194980 **Total Male Live Births** 27669

\*\*Total includes unknown race

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births

# Massachusetts

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35	35+	Total	Notes			
Down syndrome (Trisomy 21)	218 7.4	268 <b>30.9</b>	486 <b>12.8</b>				
Trisomy 13	13 <b>0.4</b>	13 <b>1.5</b>	26 <b>0.</b> 7				
Trisomy 18	32 1.1	30 <b>3.5</b>	62 <b>1.6</b>				
<b>Total Live Births</b>	293581	86826	380407				

<sup>\*\*</sup>Total includes unknown maternal age

#### Notes

- 1.Excludes isolated diagnosis without surgical intervention and secondary diagnosis without postnatal confirmation.
  2.Excludes 1st degree and not otherwise specified.

- 3.Defined as head circumference 2 standard deviations below normal.

  4.Weight <=2500 gms is excluded. We have fairly stringent criteria for coding Patent Ductus Arteriosus.
- 5.Excludes isolated unilateral renal agenesis/hypoplasia.
- 6.Excludes isolated muscular Ventricular Septal Defects.

- **General comments** -2010 data are provisional.
- -Coding system is CDC/BPA.
- -Differences in numbers from previous publications are the result of updated files.
- -Possible/probable cases are excluded.
- -Pyloric stenosis, congenital hip dislocation, epispadias, and Fetus or newborn affected by maternal alcohol use are not collected.
- -Source for race and Hispanic ethnicity is vital records.
- -Stillbirths are included, terminations are not included.

Michigan Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Anencephalus	61	12	7	2	1	89	, , , , , , ,
Aniridia	<b>1.4</b> 11	1.1 2	<b>1.6</b> 0	<b>0.9</b> 0	<b>3.5</b> 0	<b>1.5</b> 13	
Allifidia	<b>0.3</b>	0.2	0.0	0.0	0.0	0.2	
Anophthalmia/microphthalmia	58	20	4	3	0	88	
Anotia/microtia	<b>1.4</b> 51	<b>1.8</b> 12	<b>0.9</b> 4	1.4 3	<b>0.0</b>	<b>1.5</b> 71	
Allotta/filicrotta	1.2	1.1	0.9	1.4	0.0	1.2	
Aortic valve stenosis	98	13	8	7	0	132	
Admint negative description	2.3	1.2	1.8	3.3	0.0	2.2	
Atrial septal defect	3606 <b>85.3</b>	1226 <i>111.9</i>	230 <b>52.0</b>	132 <b>62.0</b>	26 <b>91.3</b>	5329 <b>87.9</b>	
Atrioventricular septal defect	242	59	13	10	0	336	
(endocardial cushion defect)	5.7	5.4	2.9	4.7	0.0	5.5	
Biliary atresia	39 <b>0.9</b>	16 <b>1.5</b>	2 <b>0.5</b>	5 <b>2.3</b>	0 <b>0.0</b>	65 <b>1.1</b>	
Bladder exstrophy	12	0	0	0	1	15	
	0.3	0.0	0.0	0.0	3.5	0.2	
Choanal atresia	68 <b>1.6</b>	18 <b>1.6</b>	1 <b>0.2</b>	2 <b>0.9</b>	0 <b>0.0</b>	92 <b>1.5</b>	
Cleft lip with and without cleft palate	493	63	26	20	2	625	
	11.7	<b>5.</b> 7	5.9	9.4	7.0	10.3	
Cleft palate without cleft lip	291 <b>6.9</b>	40 <b>3.6</b>	14 <b>3.2</b>	11 5.2	3 10.5	367 <b>6.1</b>	
Coarctation of aorta	<b>0.9</b> 279	<b>5.0</b>	23	12	4	<b>0.1</b> 391	
	6.6	5.4	5.2	5.6	14.0	6.4	
Common truncus	52	25	2	3	0	86	1
Congenital cataract	1.2 89	2.3 15	<b>0.5</b> 3	<b>1.4</b> 3	<b>0.0</b> 2	1.4 117	
	2.1	1.4	0.7	1.4	7.0	1.9	
Congenital hip dislocation	543	60	22	22	2	664	
Diaphragmatic hernia	12.8 151	5.5 30	5.0 10	10.3 6	<b>7.0</b>	11.0 207	
Diapinaginatic nerma	3.6	2.7	2.3	2.8	3.5	3.4	
Down syndrome (Trisomy 21)	578	136	39	31	3	821	
Ebstein anomaly	13.7 31	12.4 8	<b>8.8</b> 2	<b>14.6</b> 3	10.5 0	13.5 44	
Eostem anomary	<b>0.</b> 7	<b>0.</b> 7	0.5	3 1.4	0.0	<b>0.</b> 7	
Encephalocele	38	10	3	0	0	51	
E.:di	0.9	<b>0.9</b> 10	0.7	0.0	<b>0.0</b> 0	0.8	
Epispadias	31 <b>0.</b> 7	0.9	0 <b>0.0</b>	0 <b>0.0</b>	0.0	41 <b>0.</b> 7	
Esophageal atresia/tracheoesophageal	116	17	4	6	0	147	
fistula	2.7	1.6	0.9	2.8	0.0	2.4	
Fetus or newborn affected by maternal alcohol use	30 <b>0.</b> 7	17 <b>1.6</b>	0 <b>0.0</b>	1 <b>0.5</b>	0 <b>0.0</b>	49 <b>0.8</b>	
Gastroschisis	11	7	1	0	0.0	19	2
	1.4	3.3	1.2	0.0	0.0	1.7	
Hirschsprung disease (congenital megacolon)	115 <b>2.</b> 7	46 <b>4.2</b>	4 <b>0.9</b>	4 1.9	1 3.5	174 <b>2.9</b>	
Hydrocephalus without spina bifida	368	129	18	1.9 17	6	563	
	<b>8.</b> 7	11.8	4.1	8.0	21.1	9.3	
Hypoplastic left heart syndrome	159	57	7	8	1	238	1
Hypospadias*	<b>3.8</b> 1301	<b>5.2</b> 254	<b>1.6</b> 44	<b>3.8</b> 50	<b>3.5</b> 14	<b>3.9</b> 1700	
11, розращия	60.1	45.5	19.4	45.3	97.4	54.8	
Microcephalus	375	127	28	20	2	573	
Obstructive genitourinary defect	<b>8.9</b> 919	<b>11.6</b> 157	<b>6.3</b> 59	<b>9.4</b> 34	<b>7.0</b> 6	<b>9.4</b> 1203	
Jose delive genitodillary defect	21.7	137 14.3	13.3	16.0	21.1	1203 19.8	

Michigan Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity							
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Omphalocele	40	10	1	1	0	53	2	
	5.1	4.7	1.2	2.0	0.0	4.6		
Patent ductus arteriosus	1193	451	98	44	11	1821		
	28.2	41.2	22.2	20.7	38.6	30.0		
Pulmonary valve atresia and stenosis	425	164	24	20	3	648	1	
	10.0	15.0	5.4	9.4	10.5	10.7		
Pulmonary valve atresia	91	41	7	6	2	152	1	
	2.2	<b>3.</b> 7	1.6	2.8	7.0	2.5		
Pyloric stenosis	789	77	61	12	6	965		
	18.7	7.0	13.8	5.6	21.1	15.9		
Rectal and large intestinal atresia/stenosis	205	47	13	11	2	284		
-	4.8	4.3	2.9	5.2	7.0	4.7		
Reduction deformity, lower limbs	75	24	6	2	2	115		
	1.8	2.2	1.4	0.9	7.0	1.9		
Reduction deformity, upper limbs	114	29	8	2	2	157		
	2.7	2.6	1.8	0.9	7.0	2.6		
Renal agenesis/hypoplasia	215	67	16	13	3	324		
	5.1	6.1	3.6	6.1	10.5	5.3		
Spina bifida without anencephalus	225	26	16	11	1	290		
	5.3	2.4	3.6	5.2	3.5	4.8		
Tetralogy of Fallot	235	71	12	10	1	342	1	
	5.6	6.5	2.7	<b>4.</b> 7	3.5	5.6		
Total anomalous pulmonary venous return	42	20	5	5	2	76	1	
(TAPVR)	1.0	1.8	1.1	2.3	7.0	1.3		
Transposition of great arteries - All	243	54	8	14	5	334	1	
	5.7	4.9	1.8	6.6	17.6	5.5		
dextro-Transposition of great arteries	159	30	4	6	3	209	1	
(d-TGA)	3.8	2.7	0.9	2.8	10.5	3.4		
Tricuspid valve atresia and stenosis	58	18	2	2	1	82	1	
1	1.4	1.6	0.5	0.9	3.5	1.4		
Tricuspid valve atresia	58	18	2	2	1	82	1	
•	1.4	1.6	0.5	0.9	3.5	1.4		
Trisomy 13	37	12	3	2	0	57		
	0.9	1.1	0.7	0.9	0.0	0.9		
Trisomy 18	86	33	5	3	0	132		
·	2.0	3.0	1.1	1.4	0.0	2.2		
Ventricular septal defect	1776	442	112	76	10	2479		
1	42.0	40.3	25.3	35.7	35.1	40.9		
<b>Total Live Births</b>	422945	109592	44243	21279	2848	606386		
<b>Total Male Live Births</b>	216599	55811	22695	11030	1437	310432		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Michigan

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35	35+	Total**	Notes			
Down syndrome (Trisomy 21)	467	332	821				
	8.9	41.7	13.5				
Trisomy 13	44	10	57				
	0.8	1.3	0.9				
Trisomy 18	80	48	132				
	1.5	6.0	2.2				
Total Live Births	526630	79711	606386				

<sup>\*\*</sup>Total includes unknown maternal age

- Notes
  1.Live births only.
  2.Not collected until 2010.

Minnesota Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Anencephalus	2	1	4	4	1	12	Tioles
	0.3	0.5	2.9	2.6	6.6	1.0	
Aniridia	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.</b> 7	0 <b>0.0</b>	1 <b>0.1</b>	
Anophthalmia/microphthalmia	5 <b>0.8</b>	2 <b>0.9</b>	2 1.4	0 <b>0.0</b>	0 <b>0.0</b>	9 <b>0.8</b>	
Anotia/microtia	5 <b>0.8</b>	1 <b>0.5</b>	3 <b>2.1</b>	3 <b>2.0</b>	0 <b>0.0</b>	13 <b>1.1</b>	
Aortic valve stenosis	7 <b>1.1</b>	2 <b>0.9</b>	1 <b>0.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	10 <b>0.8</b>	
Atrial septal defect	89 <b>14.1</b>	47 <b>21.2</b>	26 <b>18.6</b>	25 <b>16.5</b>	1 <b>6.6</b>	205 17.1	
Atrioventricular septal defect (endocardial cushion defect)	29 <b>4.6</b>	14 <b>6.3</b>	6 <b>4.3</b>	6 <b>4.0</b>	1 <b>6.6</b>	60 <b>5.0</b>	
Biliary atresia	5	0.3	0	<b>4.0</b>	0.0	7	
	0.8	0.0	0.0	0.7	0.0	0.6	
Bladder exstrophy	1 <b>0.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.1</b>	
Choanal atresia	7 1.1	3	3 2.1	0 <b>0.0</b>	0 <b>0.0</b>	13	
Cleft lip with and without cleft palate	56 <b>8.9</b>	1.4 16 7.2	16 11.5	16 10.5	5 33.2	1.1 115 9.6	
Cleft palate without cleft lip	41	7	12	6	1	70	
Coarctation of aorta	6.5 32 5.1	3.2 11 5.0	8.6 5 3.6	4.0 6 4.0	6.6 1 6.6	5.8 62 5.2	
Common truncus	2 0.3	1 0.5	1 <b>0.</b> 7	0 <b>0.0</b>	0.0 0.0	6 <b>0.5</b>	
Congenital cataract	7 1.1	1 0.5	1 <b>0.</b> 7	1 <b>0.</b> 7	0 <b>0.0</b>	11 <b>0.9</b>	
Congenital hip dislocation	26 4.1	12 5.4	11 7.9	1 <b>0.</b> 7	1 <b>6.6</b>	52 4.3	
Diaphragmatic hernia	21 3.3	1 0.5	6 4.3	5 3.3	0.0 0.0	33 2.8	
Down syndrome (Trisomy 21)	89	45	25	15 <b>9.9</b>	3 19.9	183	
Ebstein anomaly	14.1 2 0.3	20.3 2 0.9	17.9 1 0.7	0 <b>0.0</b>	0 <b>0.0</b>	15.3 5 0.4	
Encephalocele	1 0.2	2	0	0	0	3	
Epispadias	6	<b>0.9</b>	<b>0.0</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.3</b> 7	
Esophageal atresia/tracheoesophageal	<b>1.0</b> 19	<b>0.5</b> 5	<b>0.0</b> 3	<b>0.0</b> 2	<b>0.0</b> 0	<b>0.6</b> 30	
fistula	3.0	2.3	2.1	1.3	0.0	2.5	
Gastroschisis	19 <b>3.0</b>	7 <b>3.2</b>	8 <b>5.</b> 7	10 <b>6.6</b>	1 <b>6.6</b>	46 <b>3.8</b>	
Hirschsprung disease (congenital	9	4	3	3	0	20	
megacolon) Hydrocephalus without spina bifida	1.4 16	1.8 8	2.1	2.0	<b>0.0</b>	1.7 32	
Hypoplastic left heart syndrome	2.5 17 2.7	3.6 3 1.4	4.3	0.7	<b>6.6</b> 0	2.7 25	
Hypospadias*	196	63	2.9 18	0.0 12	0.0 2 27.4	2.1 304	
Microcephalus	61.0 13 2.1	55.8 21 9.5	25.6 14 10.0	15.3 11 7.2	0 0.0	<b>49.8</b> 61 <b>5.1</b>	
Obstructive genitourinary defect	133 21.1	45 20.3	37 26.5	26 17.1	0.0 1 6.6	254 21.2	
Omphalocele	8 1.3	5 2.3	3 2.1	0 0.0	0.0 0.0	18 1.5	
Patent ductus arteriosus	99 <b>15.</b> 7	53 23.9	31 22.2	19 12.5	0.0 1 <b>6.6</b>	213 17.8	
Pulmonary valve atresia and stenosis	34 5.4	16 7.2	11 7.9	10 <b>6.6</b>	2 13.3	76 <b>6.3</b>	

Minnesota Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Pulmonary valve atresia	5 <b>0.8</b>	4 1.8	1 <b>0.</b> 7	2 1.3	1 <b>6.6</b>	13 <b>1.1</b>		
Pyloric stenosis	124 19.7	22 <b>9.9</b>	22 15.8	4 2.6	8 53.2	193 <b>16.1</b>		
Rectal and large intestinal atresia/stenosis		8 <b>3.6</b>	5 <b>3.6</b>	3 2.0	0 <b>0.0</b>	40 <b>3.3</b>		
Reduction deformity, lower limbs	4 <b>0.6</b>	5 <b>2.3</b>	1 <b>0.</b> 7	0 <b>0.0</b>	1 <b>6.6</b>	11 <b>0.9</b>		
Reduction deformity, upper limbs	9	3 1.4	3 2.1	3 2.0	2 13.3	21 1.8		
Renal agenesis/hypoplasia	22 <b>3.5</b>	8 <b>3.6</b>	8 <b>5.</b> 7	7 <b>4.6</b>	1 <b>6.6</b>	49 <b>4.1</b>		
Spina bifida without anencephalus	23 <b>3.</b> 7	2 <b>0.9</b>	4 2.9	1 <b>0.</b> 7	1 <b>6.6</b>	33 <b>2.8</b>		
Tetralogy of Fallot	30 <b>4.8</b>	8 <b>3.6</b>	2 1.4	9 <b>5.9</b>	0 <b>0.0</b>	51 <b>4.3</b>		
Transposition of great arteries - All	25 <b>4.0</b>	6 <b>2.</b> 7	5 <b>3.6</b>	7 <b>4.6</b>	0 <b>0.0</b>	47 <b>3.9</b>		
dextro-Transposition of great arteries (d-TGA)	24 <b>3.8</b>	6 <b>2.</b> 7	5 <b>3.6</b>	7 <b>4.6</b>	0 <b>0.0</b>	46 <b>3.8</b>		
Tricuspid valve atresia	4 <b>0.6</b>	3 1.4	0 <b>0.0</b>	1 <b>0.</b> 7	0 <b>0.0</b>	8 <b>0.</b> 7	1	
Trisomy 13	2 <b>0.3</b>	5 <b>2.3</b>	4 2.9	0 <b>0.0</b>	0 <b>0.0</b>	11 <b>0.9</b>		
Trisomy 18	11 1.7	8 <b>3.6</b>	1 <b>0.</b> 7	4 2.6	0 <b>0.0</b>	24 <b>2.0</b>		
Ventricular septal defect	188 <b>29.9</b>	85 <b>38.4</b>	63 <b>45.1</b>	33 21.7	6 <b>39.9</b>	395 33.0		
<b>Total Live Births</b>	62934	22137	13956	15186	1505	119785		
<b>Total Male Live Births</b>	32109	11299	7040	7859	731	61082		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

# Minnesota

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35 years old	35 years old or older	Total	Notes			
Down syndrome (Trisomy 21)	76	107	183				
	7.7	49.6	15.3				
Trisomy 13	6	5	11				
•	0.6	2.3	0.9				
Trisomy 18	10	14	24				
, and the second	1.0	6.5	2.0				
<b>Total Live Births</b>	98210	21564	119785				

<sup>\*\*</sup>Total includes unknown maternal age

### Notes

1.746.100 only included in Minnesota surveillance

- -All data include confirmed cases only
  -All data is for live births only. Stillbirths and Terminations are not included.
  -Amniotic bands are not included in Minnesota surveillance
- -Data are for Hennepin and Ramsey Counties only
- -Minnesota uses BPA codes

Mississippi Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal Ra	ace/Ethnicity				
D.G.	Non-	Non- Hispanic Black		Asian or Pacific		T-4-1++	N-4
Defect Anencephalus	Hispanic White	6	Hispanic 0	Islander 0	Alaska Native	Total**	Notes
	0.3	0.6	0.0	0.0	0.0	0.4	
Aniridia	1 <b>0.1</b>	1 <b>0.1</b>	1 1.3	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.1</b>	
Anophthalmia/microphthalmia	5	7	0	0.0	0.0	12	
	0.5	0.7	0.0	0.0	0.0	0.5	
Anotia/microtia	14 1.3	12 <b>1.2</b>	2 <b>2.</b> 7	1 <b>4.3</b>	1 <b>6.5</b>	31 <b>1.4</b>	
Aortic valve stenosis	17	9	1	0	0	28	
Atrial capital defeat	<b>1.5</b> 735	<b>0.9</b> 885	1.3 25	<b>0.0</b> 14	<b>0.0</b> 34	1.3 1729	
Atrial septal defect	66.6	90.0	33.2	59.8	222.7	78.5	
Atrioventricular septal defect	30	43	3	3	0	81	
(endocardial cushion defect) Biliary atresia	<b>2.</b> 7 5	<b>4.4</b> 7	<b>4.0</b>	12.8 0	0.0	3.7 14	
Billary attesta	0.5	0.7	1.3	0.0	0.0	0.6	
Bladder exstrophy	3	1	0	0	0	4	
Choanal atresia	<b>0.3</b> 2	<b>0.1</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b>	<b>0.2</b> 4	
	0.2	0.1	0.0	0.0	6.5	0.2	
Cleft lip with and without cleft palate	81 <i>7.3</i>	57 <b>5.8</b>	5 <b>6.6</b>	5 <b>21.4</b>	1 <b>6.5</b>	155 <b>7.0</b>	
Cleft palate without cleft lip	47	34	2	3	0.3	86	
	4.3	3.5	2.7	12.8	0.0	3.9	
Coarctation of aorta	38 <b>3.4</b>	19 <b>1.9</b>	3 <b>4.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	60 <b>2.</b> 7	
Common truncus	6	5	0	0	0	11	
	0.5	0.5	0.0	0.0	0.0	0.5	
Congenital cataract	3 <b>0.3</b>	6 <b>0.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	9 <b>0.4</b>	
Congenital hip dislocation	21	16	1	0	0	40	
Diaphragmatic hernia	1.9 21	<b>1.6</b> 24	1.3 4	<b>0.0</b> 0	0.0	1.8 51	
Diapinaginatic nerma	1.9	2.4	5.3	0.0	0.0	2.3	
Down syndrome (Trisomy 21)	100	77	9	1	1	194	
Ebstein anomaly	<b>9.1</b> 8	7.8 6	12.0	<b>4.3</b> 0	<b>6.5</b> 0	<b>8.8</b> 15	
	0.7	0.6	1.3	0.0	0.0	0.7	
Encephalocele	5 <b>0.5</b>	3 <b>0.3</b>	1 1.3	0 <b>0.0</b>	0 <b>0.0</b>	9 <b>0.4</b>	
Epispadias	3	4	0	0.0	0.0	7	
• •	0.3	0.4	0.0	0.0	0.0	0.3	
Esophageal atresia/tracheoesophageal fistula	35 <b>3.2</b>	13 1.3	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>13.1</b>	50 <b>2.3</b>	
Fetus or newborn affected by maternal	21	23	0	1	2	49	
alcohol use	1.9	2.3	0.0	4.3	13.1	2.2	1
Gastroschisis	33 <b>3.0</b>	29 <b>2.9</b>	0 <b>0.0</b>	1 <b>4.3</b>	0 <b>0.0</b>	64 <b>2.9</b>	1
Hirschsprung disease (congenital	24	36	0	1	0	63	
megacolon) Hydrocephalus without spina bifida	<b>2.2</b> 90	<b>3.7</b> 101	<b>0.0</b> 3	<b>4.3</b> 0	<b>0.0</b> 2	<b>2.9</b> 202	
Trydrocepharus without spina birida	8.2	10.3	4.0	0.0	13.1	9.2	
Hypoplastic left heart syndrome	34	26	0	0	0	60	
Hypospadias*	<b>3.1</b> 224	<b>2.6</b> 318	<b>0.0</b> 4	<b>0.0</b> 4	<b>0.0</b> 2	<b>2.7</b> 564	
	39.6	63.5	10.5	33.2	25.9	50.1	
Microcephalus	118	221	2 <b>2.</b> 7	2 <b>8.5</b>	5 <b>32.</b> 7	352 <b>16.0</b>	
Obstructive genitourinary defect	10.7 201	<b>22.5</b> 178	6	4	1	394	
	18.2	18.1	8.0	17.1	6.5	17.9	
Patent ductus arteriosus	229 <b>20.8</b>	249 <b>25.3</b>	18 <b>23.9</b>	5 <b>21.4</b>	13 <b>85.1</b>	521 <b>23.</b> 7	2
Pulmonary valve atresia and stenosis	97	121	3	3	1	229	
	8.8	12.3	4.0	12.8	6.5	10.4	

Mississippi Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Pyloric stenosis	187 <b>16.9</b>	69 7. <b>0</b>	5 <b>6.6</b>	2 <b>8.5</b>	1 <b>6.5</b>	269 12.2	
Rectal and large intestinal atresia/stenosis	24 2.2	34 3.5	3 4.0	3 12.8	1 <b>6.5</b>	68 <b>3.1</b>	
Reduction deformity, lower limbs	17 1.5	16 <b>1.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	33 1.5	
Reduction deformity, upper limbs	21 <b>1.9</b>	14 <b>1.4</b>	1 1.3	1 <b>4.3</b>	0 <b>0.0</b>	40 <b>1.8</b>	
Renal agenesis/hypoplasia	21 <b>1.9</b>	21 <b>2.1</b>	1 1.3	1 <b>4.3</b>	0 <b>0.0</b>	44 <b>2.0</b>	
Spina bifida without anencephalus	37 <b>3.4</b>	17 <b>1.7</b>	1 1.3	2 <b>8.5</b>	0 <b>0.0</b>	59 <b>2.</b> 7	
Tetralogy of Fallot	66 <b>6.0</b>	58 <b>5.9</b>	2 2.7	2 <b>8.5</b>	1 <b>6.5</b>	130 <b>5.9</b>	
Transposition of great arteries - All	39 <b>3.5</b>	43 <b>4.4</b>	3 <b>4.0</b>	4 17.1	1 <b>6.5</b>	92 <b>4.2</b>	
Tricuspid valve atresia and stenosis	16 1.5	25 <b>2.5</b>	1 1.3	2 <b>8.5</b>	0 <b>0.0</b>	46 <b>2.1</b>	
Trisomy 13	6 <b>0.5</b>	9 <b>0.9</b>	0 <b>0.0</b>	1 <b>4.3</b>	0 <b>0.0</b>	16 <b>0.</b> 7	
Trisomy 18	16 1.5	13 1.3	2 <b>2.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	32 1.5	
Ventricular septal defect	424 <b>38.4</b>	393 <b>40.0</b>	26 <b>34.6</b>	6 <b>25.6</b>	12 <b>78.6</b>	884 <b>40.1</b>	3
<b>Total Live Births</b>	110338	98344	7524	2340	1527	220198	
<b>Total Male Live Births</b>	56637	50069	3801	1204	773	112546	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

# Mississippi

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age							
Defect	Less than 35	35 and greater	Total**	Notes			
Down syndrome (Trisomy 21)	132 <b>6.5</b>	62 <b>37.5</b>	194 <b>8.8</b>				
Trisomy 13	15	1	16				
Trisomy 18	<b>0.7</b> 23	0.6	<b>0.</b> 7 32				
Trisonly 16	1.1	5.4	1.5				
Total Live Births	203629	16552	220198				

<sup>\*\*</sup>Total includes unknown maternal age

### Notes

- 1.MSDH does not distinguish between gastrochisis and omphalocele. Both are counted as gastrochisis. 2.Only cases with =>2500 grams birth weight are included. 3.MSDH does not indicate probable causes.

# **General comments**

-Mississippi uses the ICD-9 coding system.

Nebraska Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Amniotic bands	5	0	0	0	0	5	110103
	0.5	0.0	0.0	0.0	0.0	0.4	
Anencephalus	29 <b>2.9</b>	2 <b>2.3</b>	9 <b>4.4</b>	0 <b>0.0</b>	0 <b>0.0</b>	40 <b>3.0</b>	
Aniridia	1	1	0	0	0	2	
Anophthalmia/microphthalmia	<b>0.1</b> 7	1.1 0	<b>0.0</b>	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.1</b> 11	
	0.7	0.0	0.5	3.2	0.0	0.8	
Anotia/microtia	15 <b>1.5</b>	1 1.1	14 <b>6.9</b>	1 3.2	0 <b>0.0</b>	31 2.3	
Aortic valve stenosis	26	1	2	0	1	30	
Atrial septal defect	<b>2.6</b> 275	1.1 25	1.0 50	<b>0.0</b> 6	<b>4.8</b> 4	2.2 368	
Attiai septai defect	27.9	28.7	24.5	19.2	19.0	27.6	
Atrioventricular septal defect (endocardial		1	1	1	0	19	
cushion defect) Biliary atresia	<b>1.6</b> 7	<i>1.1</i> 3	<b>0.5</b> 2	3.2 0	0.0	1.4 12	
	0.7	3.4	1.0	0.0	0.0	0.9	
Bladder exstrophy	4 <b>0.4</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 <b>0.3</b>	
Choanal atresia	20	3	3	0	0	26	
Cleft lip with and without cleft palate	<b>2.0</b> 106	<b>3.4</b> 6	1.5 25	<b>0.0</b> 5	<b>0.0</b> 6	1.9 152	
	10.7	6.9	12.3	16.0	28.5	11.4	
Cleft palate without cleft lip	59 <b>6.0</b>	6 <b>6.9</b>	12 <b>5.9</b>	3 <b>9.6</b>	1 <b>4.8</b>	88 <b>6.6</b>	
Coarctation of aorta	68	0	10	2	0	82	
C	<b>6.9</b> 5	0.0	4.9	6.4	0.0	6.1	
Common truncus	0.5	0 <b>0.0</b>	1 <b>0.5</b>	0 <b>0.0</b>	1 <b>4.8</b>	7 <b>0.5</b>	
Congenital cataract	29	1	3	2	1	36	
Congenital hip dislocation	<b>2.9</b> 85	<b>1.1</b>	1.5 16	<b>6.4</b> 3	<b>4.8</b> 3	2.7 108	
	8.6	1.1	7.8	9.6	14.3	8.1	
Diaphragmatic hernia	23 2.3	2 <b>2.3</b>	7 <b>3.4</b>	0 <b>0.0</b>	1 <b>4.8</b>	33 <b>2.5</b>	
Down syndrome (Trisomy 21)	163	10	42	5	1	227	
Ebstein's anomaly	<b>16.5</b> 7	11.5 0	<b>20.6</b> 2	<b>16.0</b> 0	<b>4.8</b> 0	<b>17.0</b>	
-	0.7	0.0	1.0	0.0	0.0	0.7	
Encephalocele	5 <b>0.5</b>	2 <b>2.3</b>	4 2.0	1 3.2	0 <b>0.0</b>	13 <b>1.0</b>	
Epispadius	6	0	0	0	0	6	
Esophageal atresia/tracheoesophageal	<b>0.6</b> 17	<b>0.0</b>	<b>0.0</b> 5	<b>0.0</b> 0	0.0	<b>0.4</b> 23	
fistula	1.7	1.1	2.5	0.0	0.0	1.7	
Fetus or newborn affected by maternal	1 <b>0.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.1</b>	
alcohol use Gastroschisis	51	3	10	2	7	75	
W. I. I. I. Z. Z. Z. I.	5.2	3.4	4.9	6.4	33.3	5.6	
Hirschsprung's disease (congenital megacolon)	26 <b>2.6</b>	1 1.1	3 1.5	2 <b>6.4</b>	1 <b>4.8</b>	33 <b>2.5</b>	
Hydrocephalus without spina bifida	71	6	15	4	1	101	
Hypoplastic left heart syndrome	<b>7.2</b> 37	<b>6.9</b> 0	7.4 6	<b>12.8</b> 0	<b>4.8</b> 0	<b>7.6</b> 45	
	3.8	0.0	2.9	0.0	0.0	3.4	
Hypospadias	386 7 <b>6.4</b>	28 <b>63.0</b>	40 <b>38.2</b>	8 <b>49.3</b>	2 18.1	477 <b>69.</b> 7	
Microcephalus	68	10	23	2	3	109	
Obstructive genitourinary defect	<b>6.9</b> 167	11.5 13	11.3 30	<b>6.4</b> 7	14.3 2	<b>8.2</b> 224	
	16.9	13 14.9	14.7	22.4	9.5	16.8	
Omphalocele	27	2	3	1	0 <b>0.0</b>	34 <b>2.5</b>	
Patent ductus arteriosus	<b>2.7</b> 237	2.3 20	1.5 46	<b>3.2</b> 5	2	318	
	24.0	23.0	22.6	16.0	9.5	23.8	

Nebraska Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Pulmonary valve atresia and stenosis	70	6	6	0	1	83		
	7.1	6.9	2.9	0.0	4.8	6.2		
Pulmonary valve atresia	13	0	2	0	1	16		
	1.3	0.0	1.0	0.0	4.8	1.2		
Pyloric stenosis	179	2	28	2	1	213		
	18.2	2.3	13.7	6.4	4.8	16.0		
Rectal and large intestinal atresia/stenosis		4	11	3	1	63		
	4.2	4.6	5.4	9.6	4.8	4.7		
Reduction deformity, lower limbs	18	2	0	1	0	21		
D 1 6 10 6 11 1	1.8	2.3	0.0	3.2	0.0	1.6		
Reduction deformity, upper limbs	29 <b>2.9</b>	2	8	1 3.2	0 <b>0.0</b>	41		
D 1	46	2.3	3.9	*		<b>3.1</b> 61		
Renal agenesis/hypoplasia	4.7	2 <b>2.3</b>	11 <b>5.4</b>	1 <b>3.2</b>	0 <b>0.0</b>	4.6		
Spina bifida without anencephalus	55	7	8	3.2 1	0.0	<b>4.0</b> 71		
Spina offica without affencepharus	5.6	8.0	3.9	3.2	0.0	5.3		
Tetralogy of Fallot	28	1	4	0	1	35		
retrainegy of Fariot	2.8	1.1	2.0	0.0	4.8	<b>2.6</b>		
Total anomalous pulmonary venous return		0	6	0	0	12		
(TAPVR)	0.6	0.0	2.9	0.0	0.0	0.9		
Transposition of great arteries - All	37	2	6	0	0	46		
	3.8	2.3	2.9	0.0	0.0	3.4		
dextro-Transposition of great arteries	36	2	6	0	0	45		
(d-TGA)	3.7	2.3	2.9	0.0	0.0	3.4		
Tricuspid valve atresia and stenosis	7	2	1	0	1	13		
•	0.7	2.3	0.5	0.0	4.8	1.0		
Tricuspid valve atresia	7	2	1	0	1	13		
	0.7	2.3	0.5	0.0	4.8	1.0		
Trisomy 13	14	2	5	0	0	22		
	1.4	2.3	2.5	0.0	0.0	1.6		
Trisomy 18	31	5	5	0	1	43		
	3.1	5.7	2.5	0.0	4.8	3.2		
Ventricular septal defect	411	21	82	8	4	543		
m . 171 m a	41.7	24.1	40.2	25.6	19.0	40.7		
<b>Total Live Births</b>	98613	8713	20395	3130	2102	133497		
<b>Total Male Live Births</b>	50500	4444	10483	1623	1107	68423		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Nebraska Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age								
Defect	Less than 35	35 and greater	Total**	Notes				
Down syndrome (Trisomy 21)	129	98	227					
	10.9	64.1	17.0					
Trisomy 13	19	3	22					
	1.6	2.0	1.6					
Trisomy 18	27	16	43					
	2.3	10.5	3.2					
Total Live Births	118194	15298	133497					

<sup>\*\*</sup>Total includes unknown maternal age

- -Probable cases were not included.
- -Terminations are not a source for birth defects in Nebraska.

Nevada Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Anencephalus	0 <b>0.0</b>	1 <b>0.6</b>	8 1.1	0 <b>0.0</b>	0 <b>0.0</b>	9 <b>0.5</b>		
Anophthalmia/microphthalmia	5	3	9	0	0	17		
Anotia/microtia	<b>0.6</b> 5	1.7 0	1.2 2	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.9</b> 7		
Aortic valve stenosis	<b>0.6</b> 15	<b>0.0</b> 2	<b>0.3</b>	<b>0.0</b> 1	0.0	<b>0.4</b> 27		
	1.8	1.1	1.2	0.7	0.0	1.4		
Atrial septal defect	634 <b>77.6</b>	228 <b>130.0</b>	628 <b>84.1</b>	146 <b>95.5</b>	15 <b>66.0</b>	1681 <b>86.</b> 7		
Atrioventricular septal defect (endocardial cushion defect)	22 2.7	3 1.7	27 <b>3.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	54 <b>2.8</b>		
Biliary atresia	3	1	3	4	0	11		
Bladder exstrophy	<b>0.4</b> 1	<b>0.6</b> 0	<b>0.4</b> 3	<b>2.6</b> 0	<b>0.0</b> 0	<b>0.6</b> 4		
Choanal atresia	<b>0.1</b> 10	<b>0.0</b> 1	<b>0.4</b> 11	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.2</b> 22		
	1.2	0.6	1.5	0.0	0.0	1.1		
Cleft lip with and without cleft palate	73 <b>8.9</b>	11 <b>6.3</b>	79 <b>10.6</b>	9 <b>5.9</b>	3 13.2	178 <b>9.2</b>		
Cleft palate without cleft lip	34 <b>4.2</b>	5 <b>2.9</b>	32 4.3	3 2.0	0 <b>0.0</b>	75 <b>3.9</b>		
Coarctation of aorta	44	8	49	8	1	112		
Common truncus	5.4 4	<b>4.6</b> 0	<b>6.6</b> 7	<b>5.2</b> 2	<b>4.4</b> 0	<b>5.8</b> 13		
Congenital cataract	<b>0.5</b> 3	<b>0.0</b> 1	<b>0.9</b> 8	<b>1.3</b>	<b>0.0</b> 0	<b>0.7</b> 14		
	0.4	0.6	1.1	0.7	0.0	0.7		
Congenital hip dislocation	61 <b>7.5</b>	12 <b>6.8</b>	50 <b>6.</b> 7	7 <b>4.6</b>	2 <b>8.8</b>	136 7.0		
Diaphragmatic hernia	28 <b>3.4</b>	3 1.7	18 <b>2.4</b>	3 2.0	0 <b>0.0</b>	53 2.7		
Down syndrome (Trisomy 21)	84	24	125	17	1	258	1	
Ebstein anomaly	10.3 8	13.7 0	16.7 8	<b>11.1</b> 1	<b>4.4</b> 0	<b>13.3</b> 17		
Encephalocele	1.0 8	<b>0.0</b> 5	1.1 2	<b>0.</b> 7	<b>0.0</b> 0	<b>0.9</b> 16		
	1.0	2.9	0.3	0.0	0.0	0.8		
Epispadias	2 <b>0.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.1</b>		
Esophageal atresia/tracheoesophageal fistula	17 <b>2.1</b>	4 2.3	14 1.9	5 <b>3.3</b>	0 <b>0.0</b>	41 <b>2.1</b>		
Fetus or newborn affected by maternal	20	8	3	2	1	35		
alcohol use Hirschsprung disease (congenital	<b>2.4</b> 12	<b>4.6</b> 14	<b>0.4</b> 10	1.3 2	<b>4.4</b> 0	<b>1.8</b> 39		
megacolon)	1.5	8.0	1.3	1.3	0.0	2.0		
Hydrocephalus without spina bifida	33 <b>4.0</b>	15 <b>8.6</b>	45 <b>6.0</b>	6 <b>3.9</b>	2 <b>8.8</b>	105 <b>5.4</b>		
Hypoplastic left heart syndrome	12 <b>1.5</b>	5 <b>2.9</b>	16 <b>2.1</b>	2 1.3	0 <b>0.0</b>	38 <b>2.0</b>		
Hypospadias*	190	34	81	13	5	332		
Microcephalus	<b>45.2</b> 28	37.9 12	21.3 30	<b>16.5</b>	<b>44.3</b> 0	<i>33.5</i> 74		
Obstructive genitourinary defect	<b>3.4</b> 241	<b>6.8</b> 22	<b>4.0</b> 209	<b>0.7</b> 38	<b>0.0</b> 6	<b>3.8</b> 533		
	29.5	12.5	28.0	24.9	26.4	27.5		
Patent ductus arteriosus	554 <b>67.8</b>	191 <b>108.9</b>	553 <b>74.0</b>	128 <b>83.</b> 7	12 <b>52.8</b>	1462 <b>75.4</b>		
Pulmonary valve atresia and stenosis	63 7.7	23 <b>13.1</b>	67 <b>9.0</b>	15 <b>9.8</b>	2 <b>8.8</b>	175 <b>9.0</b>		
Pulmonary valve atresia	7	2	10	5	0	24		
Pyloric stenosis	<b>0.9</b> 119	<b>1.1</b> 14	<b>1.3</b> 119	3.3 4	<b>0.0</b> 3	1.2 275		
	14.6	8.0	15.9	2.6	13.2	14.2		

Nevada Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Rectal and large intestinal atresia/stenosis	22 <b>2.</b> 7	4 2.3	29 <b>3.9</b>	8 5.2	0 <b>0.0</b>	67 <b>3.5</b>		
Reduction deformity, lower limbs	7 <b>0.9</b>	2 1.1	11 1.5	0 <b>0.0</b>	0 <b>0.0</b>	20 1.0		
Reduction deformity, upper limbs	17 2.1	3 1.7	17 2.3	0 <b>0.0</b>	1	38 <b>2.0</b>		
Renal agenesis/hypoplasia	27 3.3	7 <b>4.0</b>	26 3.5	9 <b>5.9</b>	0 <b>0.0</b>	74 <b>3.8</b>		
Spina bifida without anencephalus	10 1.2	10 5.7	15 <b>2.0</b>	1 <b>0.</b> 7	0 <b>0.0</b>	36 1.9		
Tetralogy of Fallot	45 <b>5.5</b>	8 <b>4.6</b>	37 <b>5.0</b>	4 2.6	2 <b>8.8</b>	98 <b>5.1</b>		
Total anomalous pulmonary venous return (TAPVR)	0.5	0 <b>0.0</b>	5 <b>0.</b> 7	2 1.3	0 <b>0.0</b>	11 <b>0.6</b>		
Transposition of great arteries - All	34 4.2	6 <b>3.4</b>	34 <b>4.6</b>	1 <b>0.</b> 7	1 <b>4.4</b>	80 <b>4.1</b>	2	
dextro-Transposition of great arteries (d-TGA)	17 <b>2.1</b>	3 1.7	12 <b>1.6</b>	0 <b>0.0</b>	1 <b>4.4</b>	36 1.9		
Tricuspid valve atresia and stenosis	7 <b>0.9</b>	4 2.3	8 1.1	1 <b>0.</b> 7	1 <b>4.4</b>	22 1.1	3	
Trisomy 13	5 <b>0.6</b>	1 <b>0.6</b>	5 <b>0.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	12 <b>0.6</b>	1	
Trisomy 18	9 <b>1.1</b>	1 <b>0.6</b>	19 <b>2.5</b>	2 1.3	0 <b>0.0</b>	32 1.7	1	
Ventricular septal defect	342 <b>41.8</b>	63 <b>35.9</b>	368 <b>49.3</b>	45 <b>29.4</b>	10 <b>44.0</b>	847 <b>43.7</b>	4	
<b>Total Live Births</b>	81749	17534	74710	15289	2272	193902		
<b>Total Male Live Births</b>	42012	8980	37944	7886	1129	99138		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Nevada Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35	35+	Total**	Notes			
Down syndrome (Trisomy 21)	114 <b>6.8</b>	108 <b>40.</b> 7	258 <b>13.3</b>	1			
Trisomy 13	8 <b>0.5</b>	2 <b>0.8</b>	12 <b>0.6</b>	1			
Trisomy 18	16 <b>1.0</b>	11 <b>4.1</b>	32 1.7	1			
<b>Total Live Births</b>	167305	26557	193902				

<sup>\*\*</sup>Total includes unknown maternal age

- 1.Live births only.
- 2.Transposition of the Great Arteries: we do not use the new CDC/BPA codes; information includes the entire range.
- 3. Tricuspid Valve Atresia: do not use the new CDC/BPA codes so cases with 746.106 are included in this category.
- 4. Ventricular septal defect: excluded if less than 2500 grams birth weight or less than 36 weeks gestation; we do not use the new CDC/BPA codes - cannot distinguish BPA 745.487.

- -Data are reported for live births and Nevada resident births only.
  -Nevada uses ICD-9 Coding system.
- -Probable/possible diagnoses are excluded.
- -Still births and terminations not included (Nevada collects data on live births only)

# New Hampshire Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Amniotic bands	3	0	0	0	0	4		
Anencephalus	<b>0.5</b> 3	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.6</b> 4		
•	0.5	0.0	0.0	4.1	0.0	0.6		
Aniridia	1 <b>0.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.1</b>		
Anophthalmia/microphthalmia	3	1	0	0	0	5		
Anotia/microtia	<b>0.5</b>	<b>8.8</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b>	<b>0.7</b> 13		
	1.8	0.0	0.0	0.0	64.5	1.9		
Aortic valve stenosis	9 <b>1.5</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	11 <b>1.6</b>		
Atrial septal defect	59	1	3	4	0	81		
Atrioventricular septal defect	<b>9.6</b> 13	<b>8.8</b>	<b>38.3</b> 0	<b>16.5</b>	<b>0.0</b> 0	11.8 22		
(endocardial cushion defect)	2.1	8.8	0.0	4.1	0.0	3.2		
Biliary atresia	2 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.3</b>		
Bladder exstrophy	0	0	1	0.0	0.0	1		
	0.0	0.0	12.8	0.0	0.0	0.1		
Choanal atresia	2 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.3</b>		
Cleft lip with and without cleft palate	38	0	1	2	0	54		
Cleft palate without cleft lip	<b>6.2</b> 31	0.0	12.8 0	<b>8.2</b> 1	<b>0.0</b>	7.9 45		
	5.0	0.0	0.0	4.1	64.5	6.6		
Coarctation of aorta	17 <b>2.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	26 <b>3.8</b>		
Common truncus	3	0	0	0	0	4		
Congenital cataract	<b>0.5</b> 8	<b>0.0</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b>	<b>0.6</b> 10		
	1.3	8.8	0.0	0.0	0.0	1.5		
Congenital hip dislocation	34 <b>5.5</b>	0 <b>0.0</b>	2 <b>25.5</b>	0 <b>0.0</b>	0 <b>0.0</b>	42 <b>6.1</b>		
Diaphragmatic hernia	12	1	0	5	0.0	20		
	1.9	8.8	0.0	20.6	0.0	2.9		
Down syndrome (Trisomy 21)	49 <b>7.9</b>	1 <b>8.8</b>	1 12.8	3 12.4	1 <b>64.5</b>	70 <b>10.2</b>		
Ebstein anomaly	0	0	0	0	0	3		
Encephalocele	<b>0.0</b> 3	0.0	0.0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.4</b> 5		
	0.5	0.0	0.0	0.0	0.0	0.7		
Epispadias	2 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.3</b>		
Esophageal atresia/tracheoesophageal	11	0	0	0	0	14		
fistula Fetus or newborn affected by maternal	1.8 2	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	0.0	<b>2.0</b> 2		
alcohol use	0.3	0.0	0.0	0.0	0.0	0.3		
Gastroschisis	12 <b>1.9</b>	0 <b>0.0</b>	1 12.8	0 <b>0.0</b>	0 <b>0.0</b>	15 <b>2.2</b>	1	
Hirschsprung disease (congenital	7	0.0	2	0.0	0.0	10		
megacolon)	1.1	0.0	25.5	0.0	0.0	1.5		
Hydrocephalus without spina bifida	8 1.3	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	10 <b>1.5</b>		
Hypoplastic left heart syndrome	6	1	1	0	1	13		
Hypospadias*	1.0 218	<b>8.8</b> 3	12.8 5	<b>0.0</b> 5	<b>64.5</b> 0	1.9 264		
	69.0	50.8	126.3	40.8	0.0	75.2		
Microcephalus	22 <b>3.6</b>	1 <b>8.8</b>	1 <b>12.8</b>	1 <b>4.1</b>	0 <b>0.0</b>	30 <b>4.4</b>		
Obstructive genitourinary defect	135	3	9	5	0	192		
Omphalocele	<b>21.9</b> 7	<b>26.5</b> 0	<b>114.8</b>	<b>20.6</b> 0	0.0	<b>28.0</b> 9	1	
Omphaloccic	1.1	0.0	12.8	<b>0.0</b>	0.0	1.3	1	

New Hampshire Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

#### Maternal Race/Ethnicity American Asian or Pacific Indian or White Black Islander Alaska Native Non-Hispanic Defect Non-Hispanic Non-Hispanic Hispanic Total\*\* Notes Non-Hispanic Patent ductus arteriosus 32 2 4.0 17.7 0.0 4.1 0.0 4.7 Pulmonary valve atresia and stenosis 32 3 47 4.1 0.0 6.9 5.2 26.5 12.8 Pyloric stenosis 121 160 0.0 38.3 19.6 8.2 64.5 23.3 Rectal and large intestinal atresia/stenosis 17 0 0 26 0.0 0.0 0.0 2.8 25.5 3.8 Reduction deformity, lower limbs 0.0 0.0 0.0 0.0 **0.**7 0.6 Reduction deformity, upper limbs 18 12 0 0.0 0.0 1.9 0.0 12.8 2.6 Renal agenesis/hypoplasia 37 51 0 0 6.0 0.0 4.1 0.0 51.0 7.4 Spina bifida without anencephalus 10 14 0.0 0.0 0.0 1.6 12.8 2.0 Tetralogy of Fallot 12 26 1.9 8.8 38.3 4.1 0.0 3.8 Transposition of great arteries - All 9 20 0 0 8.8 0.0 1.5 12.8 0.0 2.9 Tricuspid valve atresia and stenosis 0.0 0.0 0.0 0.0 0.0 0.1 Trisomy 13 0.5 8.8 0.0 0.0 0.0 0.7 Trisomy 18 0 0 0 11 1.0 0.0 0.0 0.0 0.0 1.6 Ventricular septal defect 129 3 89 0.0 14.4 17.7 38.3 12.4 18.8 **Total Live Births** 784 2427 155 68586 61736 1133 590 396 1226 74 35113 **Total Male Live Births** 31606

\*\*Total includes unknown race

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births

# **New Hampshire**

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35	35+	Total**	Notes			
Down syndrome (Trisomy 21)	47 <b>8.3</b>	21 <b>17.6</b>	70 <b>10.2</b>				
Trisomy 13	1 <b>0.</b> 2	3 <b>2.5</b>	5 <b>0.</b> 7				
Trisomy 18	5 <b>0.9</b>	6 <b>5.0</b>	11 <b>1.6</b>				
Total Live Births	56477	11913	68586				

<sup>\*\*</sup>Total includes unknown maternal age

#### Notes

- 1.ICD-9 code data and active medical record abstraction used for all gastroschisis and omphalocele cases. For gastroschisis and omphalocele, cases are distinguished using active medical chart review.
- 2.Includes weight greater than or equal to 2500 grams only.
- 3. Probable cases not included.

- -Data for all birth conditions includes data ascertained during calendar years 2006 through 2010 for NH resident mothers.
- -Data for live births was obtained from the New Hampshire Department of State, Division of Vital Records Administration, Web Query Tool. Data may vary from year to year due to the process of continuing acquisition of birth certificate information, particularly from NH residents that give birth out of state.
- -Data includes live births from birth to age 2 years, stillbirths and terminations.
- -Data is for confirmed cases only, following medical chart review and use of the NBDPN Guidelines.

New Jersey Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Amniotic bands	10	9	18	0	0	38	1	
Anencephalus	<b>0.4</b> 6	1.1 2	1.3 7	0.0	0.0	<b>0.7</b> 16		
Aniridia	<b>0.2</b> 7	0.2	<b>0.5</b> 2	0.2	<b>0.0</b> 0	<b>0.3</b> 10		
	0.3	0.0	0.1	0.0	0.0	0.2		
Anophthalmia/microphthalmia	19 <b>0.</b> 7	8 <b>1.0</b>	24 <b>1.</b> 7	6 <b>1.1</b>	0 <b>0.0</b>	58 <b>1.1</b>		
Anotia/microtia	38 <b>1.5</b>	12 1.4	56 <b>3.9</b>	9 <b>1.7</b>	0 <b>0.0</b>	119 <b>2.2</b>		
Aortic valve stenosis	30	6	14	1	0	54		
Atrial septal defect	1.2 598	<b>0.7</b> 415	1.0 523	0.2 135	0.0 7 112.2	1.0 1723	2	
Atrioventricular septal defect	<b>23.4</b> 77	<b>49.9</b> 28	<b>36.6</b> 36	<b>24.9</b> 9	1	<b>31.2</b> 155		
(endocardial cushion defect)	3.0	3.4	2.5	1.7	16.0	2.8		
Biliary atresia	7 <b>0.3</b>	8 1.0	11 <b>0.8</b>	4 <b>0. 7</b>	0 <b>0.0</b>	31 <b>0.6</b>		
Bladder exstrophy	2 <b>0.1</b>	1 <b>0.1</b>	3 <b>0.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	6 <b>0.1</b>		
Choanal atresia	34	17	27	2	0 <b>0.0</b>	82		
Cleft lip with and without cleft palate	<b>1.3</b> 197	<b>2.0</b> 41	<b>1.9</b> 134	<b>0.4</b> 54	2	<b>1.5</b> 440		
Cleft palate without cleft lip	7.7 141	<b>4.9</b> 38	<b>9.4</b> 104	<b>9.9</b> 45	<b>32.1</b> 0	<b>8.0</b> 340		
Coarctation of aorta	<b>5.5</b> 95	<b>4.6</b> 25	<b>7.3</b> 52	<b>8.3</b> 11	<b>0.0</b>	<b>6.2</b> 190		
	3.7	3.0 3	3.6 14	2.0	16.0 0	3.4 27		
Common truncus	0.4	0.4	1.0	0.2	0.0	0.5		
Congenital cataract	37 <b>1.5</b>	18 2.2	43 <b>3.0</b>	5 <b>0.9</b>	1 <b>16.0</b>	106 <b>1.9</b>		
Congenital hip dislocation	114 <b>4.5</b>	21 2.5	61 <b>4.3</b>	27 <b>5.0</b>	1 <b>16.0</b>	230 <b>4.2</b>		
Diaphragmatic hernia	33 1.3	7 <b>0.8</b>	28 <b>2.0</b>	9 <b>1.</b> 7	0 <b>0.0</b>	80 1.4		
Down syndrome (Trisomy 21)	307 12.0	102 12.3	200 14.0	38 7.0	3 48.1	672 12.2		
Ebstein anomaly	16	5	14	1	0	36		
Encephalocele	<b>0.6</b> 15	<b>0.6</b> 4	1.0 8	<b>0.2</b> 4	<b>0.0</b> 0	<b>0.7</b> 32		
Epispadias	<b>0.6</b> 55	<b>0.5</b> 18	<b>0.6</b> 28	<b>0.</b> 7	<b>0.0</b>	<b>0.6</b> 112		
• •	2.2	2.2	2.0	1.1	16.0	2.0		
Esophageal atresia/tracheoesophageal fistula	64 <b>2.5</b>	15 <b>1.8</b>	32 2.2	6 <b>1.1</b>	0 <b>0.0</b>	119 <b>2.2</b>		
Fetus or newborn affected by maternal	6	11	0	0	1	19		
alcohol use Gastroschisis	<b>0.2</b> 49	1.3 23	<b>0.0</b> 45	<b>0.0</b> 4	<b>16.0</b>	<b>0.3</b> 124	3	
Hirschsprung disease (congenital	<b>1.9</b> 49	<b>2.8</b> 23	3.2 24	<b>0.</b> 7 8	<b>16.0</b> 0	<b>2.2</b> 107		
megacolon)	1.9	2.8	1.7	1.5	0.0	1.9		
Hydrocephalus without spina bifida	70 <b>2.</b> 7	51 <b>6.1</b>	81 <b>5.</b> 7	8 1.5	0 <b>0.0</b>	215 <b>3.9</b>		
Hypoplastic left heart syndrome	35 <b>1.4</b>	14 <b>1.</b> 7	30 <b>2.1</b>	2 <b>0.4</b>	0 <b>0.0</b>	86 <b>1.6</b>		
Hypospadias*	1349 <b>103.4</b>	317 <b>74.6</b>	386 <b>53.0</b>	173 <b>62.1</b>	6 184.6	2285 <b>81.0</b>		
Microcephalus	112	74	131	33	0	360		
Obstructive genitourinary defect	<b>4.4</b> 1179	<b>8.9</b> 286	<b>9.2</b> 587	<b>6.1</b> 198	<b>0.0</b> 5	<b>6.5</b> 2295		
Omphalocele	<b>46.2</b> 20	<b>34.4</b> 21	<b>41.1</b> 14	<b>36.5</b> 4	<b>80.1</b> 0	<b>41.6</b> 60	3	
	0.8	2.5	1.0	0.7	0.0	1.1		

New Jersey Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Patent ductus arteriosus	1519	725	971	279	5	3542		
Pulmonary valve atresia and stenosis	59.6 247 9.7	<b>87.1</b> 120 <b>14.4</b>	<b>68.0</b> 128 <b>9.0</b>	51.4 37 6.8	80.1 1 16.0	<b>64.2</b> 544 <b>9.9</b>		
Pulmonary valve atresia	18 <b>0.</b> 7	13 <b>1.6</b>	14 1.0	3 <b>0.6</b>	0 <b>0.0</b>	51 <b>0.9</b>		
Pyloric stenosis	433 17.0	66 <b>7.9</b>	257 <b>18.0</b>	28 <b>5.2</b>	0 <b>0.0</b>	811 <b>14.7</b>		
Rectal and large intestinal atresia/stenosis	3.1	21 2.5	53 <b>3.</b> 7	19 <b>3.5</b>	1 <b>16.0</b>	178 3.2		
Reduction deformity, lower limbs	53 <b>2.1</b>	29 <b>3.5</b>	27 <b>1.9</b>	9 <b>1.</b> 7	0 <b>0.0</b>	122 <b>2.2</b>		
Reduction deformity, upper limbs	58 <b>2.3</b>	32 <b>3.8</b>	50 <b>3.5</b>	12 2.2	0 <b>0.0</b>	160 <b>2.9</b>		
Renal agenesis/hypoplasia	141 <b>5.5</b>	36 <b>4.3</b>	71 <b>5.0</b>	13 <b>2.4</b>	1 <b>16.0</b>	271 <b>4.9</b>		
Spina bifida without anencephalus	70 <b>2.</b> 7	25 <b>3.0</b>	54 <b>3.8</b>	7 <b>1.3</b>	1 <b>16.0</b>	163 <b>3.0</b>		
Tetralogy of Fallot	77 <b>3.0</b>	45 <b>5.4</b>	49 <b>3.4</b>	20 <b>3.</b> 7	0 <b>0.0</b>	203 3.7		
Total anomalous pulmonary venous return (TAPVR)	16 <b>0.6</b>	9 <b>1.1</b>	16 <b>1.1</b>	1 <b>0.2</b>	0 <b>0.0</b>	42 <b>0.8</b>		
Transposition of great arteries - All	67 <b>2.6</b>	35 <b>4.2</b>	43 <b>3.0</b>	15 <b>2.8</b>	0 <b>0.0</b>	168 <b>3.0</b>		
dextro-Transposition of great arteries (d-TGA)	45 1.8	15 <b>1.8</b>	24 1.7	9 <b>1.7</b>	0 <b>0.0</b>	98 <b>1.8</b>		
Tricuspid valve atresia and stenosis	14 <b>0.5</b>	11 <b>1.3</b>	10 <b>0. 7</b>	3 <b>0.6</b>	0 <b>0.0</b>	39 <b>0. 7</b>		
Trisomy 13	5 <b>0.2</b>	4 <b>0.</b> 5	6 <b>0.4</b>	1 <b>0.2</b>	0 <b>0.0</b>	17 <b>0.3</b>		
Trisomy 18	20 <b>0.8</b>	15 <b>1.8</b>	17 <b>1.2</b>	5 <b>0.9</b>	0 <b>0.0</b>	57 <b>1.0</b>		
Ventricular septal defect	1583 <b>62.1</b>	480 <b>57.</b> 7	915 <b>64.1</b>	264 <b>48.6</b>	7 112.2	3299 <b>59.8</b>	4	
<b>Total Live Births</b>	255042	83229	142833	54273	624	552040		
<b>Total Male Live Births</b>	130476	42504	72837	27845	325	282238		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

**New Jersey** Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35	35+	Total	Notes			
Down syndrome (Trisomy 21)	279	350	672				
	6.4	29.7	12.2				
Trisomy 13	10	7	17				
•	0.2	0.6	0.3				
Trisomy 18	27	30	57				
•	0.6	2.5	1.0				
Total Live Births	434084	117855	552040				

<sup>\*\*</sup>Total includes unknown maternal age

- 1.Used codes 658.80 and 762.80.
  2.ASD only, PFO coded separately.
  3.Gastroschisis coded 756.79, Omphalocele coded 756.78.
- 4.Only confirmed cases included.

- -Hybrid system; Passive with audit, uses ICD9-CM; 2010 live birth file is not final and is missing about 3000 out-of-state births; New web-based system implemented on July 1, 2009 with reduced reporting of prematurity-related and minor diagnoses. -New Jersey collects live births only.

New York Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity							
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Amniotic bands	32	14	19	2	0	67		
Anencephalus	0.5 20 0.3	0.7 8 0.4	<b>0.7</b> 16 <b>0.6</b>	0.2 2 0.2	0.0 0 0.0	0.5 47 0.4	1	
Aniridia	10	2	5	1	0.0	18		
	0.2	0.1	0.2	0.1	0.0	0.1		
Anophthalmia/microphthalmia	58 <b>1.0</b>	21 <b>1.1</b>	46 <b>1.</b> 7	17 <b>1.4</b>	0 <b>0.0</b>	143 1.2		
Anotia/microtia	60 <b>1.0</b>	8 <b>0.4</b>	52 1.9	11 <b>0.9</b>	1 4.3	134 1.1		
Aortic valve stenosis	145 2.5	21 1.1	48 1.7	12 1.0	0 <b>0.0</b>	229 1.9		
Atrial septal defect	2129 36.0	1380	1.7 1289 46.7	584 <b>46.5</b>	8 34.8	5493 45.1		
Atrioventricular septal defect	256	<b>69.6</b> 126	108	46	1	548		
(endocardial cushion defect)	4.3	6.4	3.9	3.7	4.3	4.5		
Biliary atresia	45 <b>0.8</b>	41 <b>2.1</b>	34 1.2	22 1.8	1 4.3	144 1.2		
Bladder exstrophy	18 <b>0.3</b>	2 <b>0.1</b>	0 <b>0.0</b>	1 <b>0.1</b>	0 <b>0.0</b>	21 <b>0.2</b>		
Choanal atresia	135 2.3	37 1.9	49 1.8	9 <b>0.</b> 7	0 <b>0.0</b>	231 1.9		
Cleft lip with and without cleft palate	481 <b>8.1</b>	89 4.5	210 7.6	76 <b>6.1</b>	3 13.0	877 7.2		
Cleft palate without cleft lip	362	95	136	73 5.8	13.0 1 4.3	680		
Coarctation of aorta	6.1 332	<b>4.8</b> 109	<b>4.9</b> 144	48	1	<b>5.6</b> 647		
Common truncus	5.6 31	5.5 20	5.2	3.8 8	<b>4.3</b> 0	5.3 71		
Congenital cataract	<b>0.5</b> 112	1.0 54	<b>0.4</b> 53	<b>0.6</b> 16	0.0	<b>0.6</b> 240	2	
Congenital hip dislocation	1.9 580	2.7 69	1.9 260	1.3 83	0.0	2.0 1005		
Diaphragmatic hernia	<b>9.8</b> 155	<b>3.5</b> 38	<b>9.4</b> 56	<b>6.6</b> 23	<b>0.0</b>	<b>8.2</b> 279		
	2.6	1.9	2.0	1.8	4.3	2.3		
Down syndrome (Trisomy 21)	735 <b>12.4</b>	263 13.3	357 <b>12.9</b>	92 <b>7.3</b>	1 4.3	1484 12.2		
Ebstein anomaly	33 <b>0.6</b>	12 <b>0.6</b>	18 <b>0. 7</b>	6 <b>0.5</b>	0 <b>0.0</b>	71 <b>0.6</b>		
Encephalocele	43	20	20	10	0.0	95		
	0.7	1.0	0.7	0.8	0.0	0.8		
Epispadias	105 <b>1.8</b>	55 <b>2.8</b>	52 <b>1.9</b>	12 <b>1.0</b>	0 <b>0.0</b>	228 1.9		
Esophageal atresia/tracheoesophageal fistula	172 <b>2.9</b>	38 <b>1.9</b>	59 <b>2.1</b>	22 1.8	0 <b>0.0</b>	302 2.5		
Fetus or newborn affected by maternal	26	27	15	0	0	70		
alcohol use Gastroschisis	<b>0.4</b> 154	1.4 46	<b>0.5</b> 77	<b>0.0</b> 8	<b>0.0</b> 4	<b>0.6</b> 293	3	
Hirschsprung disease (congenital	<b>2.6</b> 171	<b>2.3</b> 83	<b>2.8</b> 50	<b>0.6</b> 23	17.4 0	<b>2.4</b> 334		
megacolon)	2.9	4.2	1.8	1.8	0.0	2.7		
Hydrocephalus without spina bifida	422 <b>7.1</b>	235 11.9	237 <b>8.6</b>	76 <b>6.1</b>	2 <b>8.</b> 7	995 <b>8.2</b>		
Hypoplastic left heart syndrome	164 <b>2.8</b>	52 <b>2.6</b>	72 <b>2.6</b>	21 1.7	3 13.0	319 <b>2.6</b>		
Hypospadias*	2891 <b>95.2</b>	669 66.2	669 47.5	292 <b>45.0</b>	8 71.0	4619 74.0	4	
Microcephalus	319 5.4	199 <b>10.0</b>	224 <b>8.1</b>	56 4.5	2 8.7	819 <b>6.</b> 7		
Obstructive genitourinary defect	2431	626	1074	604	11	4834		
Omphalocele	41.1 70	31.6 32	<b>38.9</b> 30	<b>48.1</b> 15	47.8 3 13.0	<b>39.7</b> 153		
	1.2	1.6	1.1	1.2	13.0	1.3		

**New York** Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Patent ductus arteriosus	1813	1012	697	390	13	4015	
	30.7	51.0	25.3	31.1	56.5	33.0	
Pulmonary valve atresia and stenosis	463 <b>7.8</b>	230 11.6	216 7.8	94 <b>7.5</b>	2 <b>8.</b> 7	1030 <b>8.5</b>	
Pulmonary valve atresia	52	25	33	13	0	126	
i unifoliary varve attesta	0.9	1.3	1.2	1.0	0.0	1.0	
Pyloric stenosis	1492	250	741	130	9	2657	
- ,	25.2	12.6	26.9	10.4	39.1	21.8	
Rectal and large intestinal atresia/stenosis	239	67	134	50	1	502	
	4.0	3.4	4.9	4.0	4.3	4.1	
Reduction deformity, lower limbs	53	32	21	6	1	117	
	0.9	1.6	0.8	0.5	4.3	1.0	
Reduction deformity, upper limbs	159	41	61	12	1	279	
Danal aganasis/hymanlasis	<b>2.</b> 7 302	<b>2.1</b> 88	<b>2.2</b> 107	<b>1.0</b> 41	<b>4.3</b> 2	<b>2.3</b> 554	
Renal agenesis/hypoplasia	5.1	00 4.4	3.9	3.3	<b>8.</b> 7	4.5	
Spina bifida without anencephalus	139	39	63	26	0	272	
Spina offica without anenecpharas	2.4	2.0	2.3	2.1	0.0	2.2	
Tetralogy of Fallot	300	101	99	64	2	582	
	5.1	5.1	3.6	5.1	<b>8.</b> 7	4.8	
Total anomalous pulmonary venous return		23	42	13	0	136	
(TAPVR)	1.0	1.2	1.5	1.0	0.0	1.1	
Transposition of great arteries - All	174	47	62	28	0	320	
1 4 7 36 6 4 4 5	2.9	2.4	2.2	2.2	0.0	2.6	
dextro-Transposition of great arteries (d-TGA)	165 <b>2.8</b>	47 <b>2.4</b>	62 <b>2.2</b>	26 <b>2.1</b>	0 <b>0.0</b>	309 <b>2.5</b>	
Tricuspid valve atresia and stenosis	52	41	42	18	0.0	158	
Theuspia varve attesta and stenosis	0.9	2.1	1.5	1.4	0.0	1.3	
Tricuspid valve atresia	28	15	18	9	0	71	
	0.5	0.8	0.7	0.7	0.0	0.6	
Trisomy 13	42	18	22	8	0	90	
	0.7	0.9	0.8	0.6	0.0	0.7	
Trisomy 18	54	38	41	10	0	146	
V	0.9	1.9	1.5	0.8	0.0	1.2	
Ventricular septal defect	2806	823	1283	507	12 <b>52.1</b>	5534	
<b>Total Live Births</b>	<i>47.4</i> 591438	41.5 198275	46.5 275951	40.4 125493	32.1 2302	45.4 1218258	
Total Live Diffus	371430	1704/3	413731	143473	2302	1410430	
<b>Total Male Live Births</b>	303652	101036	140866	64926	1127	624350	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

New York Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)						
Defect	Less than 35	35+	Total	Notes		
Down syndrome (Trisomy 21)	712 7.3	772 32.2	1484 <b>12.2</b>			
Trisomy 13	63 <b>0.6</b>	27 <b>1.1</b>	90 <b>0.</b> 7			
Trisomy 18	65 <b>0.</b> 7	81 <b>3.4</b>	146 1.2			
Total Live Births	978555	239476	1218258			

<sup>\*\*</sup>Total includes unknown maternal age

North Carolina Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Amniotic bands	53 1.5	24 1.6	13 1.3	4 2.0	4 <b>4.6</b>	100 <b>1.6</b>		
Anencephalus	86 2.4	28 1.9	37 3.6	6 3.0	4.6 4.6	178 2.8		
Aniridia	2.4	4	1	1	0	8		
Anophthalmia/microphthalmia	<b>0.1</b> 55	<b>0.3</b> 32	<b>0.1</b> 23	<b>0.5</b> 4	<b>0.0</b>	<b>0.1</b> 115		
Апоришанна/писторишанна	1.6	2.1	2.2	2.0	1.1	1.8		
Anotia/microtia	48 <b>1.4</b>	15 <b>1.0</b>	35 <b>3.4</b>	5 <b>2.5</b>	6 <b>6.9</b>	110 <b>1.7</b>		
Aortic valve stenosis	93	36	24	2	3	158		
A414-1 J-54	2.6	2.4	2.3	1.0	3.4	2.5		
Atrial septal defect	1541 <b>43.5</b>	856 <b>56.9</b>	433 <b>41.</b> 7	64 <b>32.2</b>	65 <b>74.3</b>	2968 <b>46.5</b>		
Atrioventricular septal defect (endocardial cushion defect)		96	61 <b>5.9</b>	9 <b>4.5</b>	7 <b>8.0</b>	403		
Biliary atresia	<b>6.4</b> 21	<b>6.4</b> 16	9	0	1	<b>6.3</b> 47		
	0.6	1.1	0.9	0.0	1.1	0.7		
Bladder exstrophy	8 <b>0.2</b>	8 <b>0.5</b>	3 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	19 <b>0.3</b>		
Choanal atresia	46	21	17	2	1	87		
Cleft lip with and without cleft palate	<b>1.3</b> 347	<b>1.4</b> 104	<b>1.6</b> 92	<b>1.0</b> 17	<b>1.1</b> 13	<b>1.4</b> 574		
	9.8	6.9	8.9	8.6	14.9	9.0		
Cleft palate without cleft lip	267 7.5	57 <b>3.8</b>	50 <b>4.8</b>	17 <b>8.6</b>	7 <b>8.0</b>	399 <b>6.3</b>		
Coarctation of aorta	198 <b>5.6</b>	66 <b>4.4</b>	43 <b>4.1</b>	10 <b>5.0</b>	6 <b>6.9</b>	324 <b>5.1</b>		
Common truncus	30	14	9	2	1	56		
Congenital cataract	<b>0.8</b> 38	<b>0.9</b> 29	<b>0.9</b> 8	<b>1.0</b> 3	<b>1.1</b>	<b>0.9</b> 79		
	1.1	1.9	0.8	1.5	1.1	1.2		
Diaphragmatic hernia	101 2.8	32 <b>2.1</b>	29 <b>2.8</b>	7 <b>3.5</b>	3 <b>3.4</b>	174 <b>2.</b> 7		
Down syndrome (Trisomy 21)	434	143	143	26	14	771		
Ebstein anomaly	12.2 33	<b>9.5</b> 9	13.8 9	13.1 6	16.0 0	12.1 57		
	0.9	0.6	0.9	3.0	0.0	0.9		
Encephalocele	42 1.2	19 <b>1.3</b>	16 <b>1.5</b>	2 1.0	2 <b>2.3</b>	82 <b>1.3</b>		
Epispadias	29	18	3	0	0	50		
Esophageal atresia/tracheoesophageal	<b>0.8</b> 97	<b>1.2</b> 27	<b>0.3</b> 16	<b>0.0</b> 3	<b>0.0</b> 3	<b>0.8</b> 146		
fistula	2.7	1.8	1.5	1.5	3.4	2.3		
Gastroschisis	155 <b>4.4</b>	63 <b>4.2</b>	45 <b>4.3</b>	6 <b>3.0</b>	6 <b>6.9</b>	278 <b>4.4</b>		
Hirschsprung disease (congenital	87	59	11	5	1	163		
megacolon) Hydrocephalus without spina bifida	<b>2.5</b> 344	<b>3.9</b> 189	<b>1.1</b> 95	<b>2.5</b> 14	1.1 10	<b>2.6</b> 660		
	9.7	12.6	9.2	7.0	11.4	10.3		
Hypoplastic left heart syndrome	92 <b>2.6</b>	38 <b>2.5</b>	27 <b>2.6</b>	3 1.5	1 1.1	162 <b>2.5</b>		
Hypospadias*	1215	410	121	49	34	1831		
Microcephalus	<b>66.7</b> 151	<b>53.5</b> 101	<b>22.8</b> 47	<b>47.4</b> 9	<b>76.6</b> 3	<b>56.0</b> 312		
	4.3	<b>6.</b> 7	4.5	4.5	3.4	4.9		
Obstructive genitourinary defect	1386 <b>39.1</b>	551 <b>36.6</b>	375 <b>36.1</b>	72 <b>36.2</b>	39 <b>44.6</b>	2430 <b>38.1</b>		
Omphalocele	73	35	19	8	0 <b>0.0</b>	135		
Patent ductus arteriosus	<b>2.1</b> 1199	<b>2.3</b> 554	1.8 378	<b>4.0</b> 59	36	2.1 2229		
Pulmonary valve atresia and stenosis	<b>33.8</b> 264	<b>36.8</b> 145	<b>36.4</b> 83	<b>29.7</b> 12	<b>41.2</b> 7	<b>34.9</b> 511		
i annonary varve arresta and stenosis	7.4	9.6	8.0	6.0	8.0	8.0		

**North Carolina** Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Pulmonary valve atresia	45 1.3	34 <b>2.3</b>	17 <b>1.6</b>	5 <b>2.5</b>	1 1.1	102 1.6	
Pyloric stenosis	734 <b>20.</b> 7	91 <b>6.0</b>	198 <b>19.1</b>	8 <b>4.0</b>	23 <b>26.3</b>	1056 <b>16.5</b>	
Rectal and large intestinal atresia/stenosis	147 <b>4.1</b>	59 <b>3.9</b>	61 <b>5.9</b>	5 <b>2.5</b>	5 <b>5. 7</b>	279 <b>4.4</b>	
Reduction deformity, lower limbs	61 1.7	31 <b>2.1</b>	19 <b>1.8</b>	3 1.5	4 <b>4.6</b>	119 <b>1.9</b>	
Reduction deformity, upper limbs	126 <b>3.6</b>	62 <b>4.1</b>	34 <b>3.3</b>	6 <b>3.0</b>	8 <b>9.1</b>	237 <b>3.</b> 7	
Renal agenesis/hypoplasia	245 <b>6.9</b>	107 7.1	70 <b>6.</b> 7	11 <b>5.5</b>	9 <b>10.3</b>	445 7.0	
Spina bifida without anencephalus	153 <b>4.3</b>	43 <b>2.9</b>	59 <b>5. 7</b>	8 <b>4.0</b>	2 2.3	268 4.2	
Tetralogy of Fallot	156 <b>4.4</b>	77 <b>5.1</b>	33 <b>3.2</b>	10 <b>5.0</b>	9 <b>10.3</b>	287 <b>4.5</b>	
Total anomalous pulmonary venous return (TAPVR)	39 1.1	15 <b>1.0</b>	19 <b>1.8</b>	5 <b>2.5</b>	2 <b>2.3</b>	80 1.3	
Transposition of great arteries - All	117 <b>3.3</b>	37 <b>2.5</b>	30 <b>2.9</b>	8 <b>4.0</b>	4 <b>4.6</b>	196 <b>3.1</b>	
dextro-Transposition of great arteries (d-TGA)	104 <b>2.9</b>	34 <b>2.3</b>	24 2.3	6 <b>3.0</b>	3 <b>3.4</b>	171 <b>2.</b> 7	
Tricuspid valve atresia and stenosis	62 1.7	34 <b>2.3</b>	24 2.3	1 <b>0.5</b>	5 <b>5. 7</b>	126 <b>2.0</b>	
Tricuspid valve atresia	50 1.4	31 <b>2.1</b>	21 2.0	1 <b>0.5</b>	4 <b>4.6</b>	107 <b>1.</b> 7	
Trisomy 13	34 1.0	23 <b>1.5</b>	14 1.3	2 <b>1.0</b>	1 1.1	76 1.2	
Trisomy 18	99 <b>2.8</b>	38 <b>2.5</b>	25 <b>2.4</b>	10 <b>5.0</b>	2 2.3	181 <b>2.8</b>	
Ventricular septal defect	1503 <b>42.4</b>	619 <b>41.1</b>	559 <b>53.8</b>	67 <b>33.</b> 7	44 50.3	2796 <b>43.8</b>	
<b>Total Live Births</b>	354429	150454	103812	19865	8745	638377	
<b>Total Male Live Births</b>	182123	76589	53047	10331	4439	327062	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

North Carolina

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)						
Defect	Less than 35	35+	Total**	Notes		
Down syndrome (Trisomy 21)	431	337	771			
	7.7	41.2	12.1			
Trisomy 13	56 <b>1.0</b>	20 <b>2.4</b>	76 1.2			
Trisomy 18	100	79	181			
TO A LET . DO A	1.8	9.7	2.8			
<b>Total Live Births</b>	556641	81703	638377			

<sup>\*\*</sup>Total includes unknown maternal age

North Dakota Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Anencephalus	24 <b>6.</b> 7	1 13.9	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	25 <b>5.6</b>	
Anophthalmia/microphthalmia	1	0	0	0	0	1	
Anotia/microtia	<b>0.3</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 2	<b>0.2</b> 2	
Aortic valve stenosis	<b>0.0</b> 9	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>4.2</b>	<b>0.5</b> 10	
	2.5	0.0	0.0	0.0	2.1	2.3	
Atrial septal defect	243 <b>67.</b> 7	9 <b>124.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	84 176.1	342 77. <b>0</b>	
Atrioventricular septal defect	6	0	0	0	4	11	1
(endocardial cushion defect) Biliary atresia	1.7 2	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>8.4</b> 1	2.5 3	
Bladder exstrophy	<b>0.6</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>2.1</b> 0	<b>0.</b> 7	
	0.3	0.0	0.0	0.0	0.0	0.2	
Choanal atresia	3 <b>0.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.</b> 7	
Cleft lip with and without cleft palate	56	0	0	0	11	70	
Cleft palate without cleft lip	<b>15.6</b> 59	<b>0.0</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>23.1</b> 7	<b>15.8</b> 67	
Coarctation of aorta	<b>16.4</b> 11	<b>13.9</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>14.7</b>	<b>15.1</b> 12	
	3.1	0.0	0.0	0.0	2.1	2.7	
Common truncus	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 4.2	2 <b>0.5</b>	
Congenital cataract	7 <b>2.0</b>	1 13.9	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>2.1</b>	10 2.3	
Diaphragmatic hernia	14	0	0	0	5	19	
Down syndrome (Trisomy 21)	<b>3.9</b> 35	<b>0.0</b>	<b>0.0</b> 0	<b>0.0</b> 2	<b>10.5</b> 0	<b>4.3</b> 41	
	9.8	13.9	0.0	33.2	0.0	9.2	
Ebstein anomaly	5 <b>1.4</b>	1 13.9	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>2.1</b>	7 <b>1.6</b>	
Encephalocele	1 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>2.1</b>	2 <b>0.5</b>	
Esophageal atresia/tracheoesophageal	18	1	0	0	1	20	
fistula Fetus or newborn affected by maternal	<b>5.0</b>	13.9 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>2.1</b> 2	<b>4.5</b> 3	
alcohol use	0.3	0.0	0.0	0.0	4.2	0.7	2
Gastroschisis	21 <b>5.9</b>	2 27.7	0 <b>0.0</b>	1 <b>16.6</b>	16 <b>33.5</b>	40 <b>9.0</b>	2
Hirschsprung disease (congenital megacolon)	8 2.2	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>6.3</b>	11 <b>2.5</b>	
Hydrocephalus without spina bifida	17	0	0	0	6	25	
Hypoplastic left heart syndrome	<b>4.7</b> 12	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>12.6</b>	<b>5.6</b> 13	
Hypospadias*	<b>3.3</b> 53	<b>0.0</b> 2	<b>0.0</b> 0	<b>0.0</b> 1	<b>2.1</b> 5	<b>2.9</b> 61	3
	28.9	48.1	0.0	40.8	19.4	26.9	3
Microcephalus	13 <b>3.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>2.1</b>	15 <b>3.4</b>	
Obstructive genitourinary defect	4	0	0	0	0	4	
Omphalocele	1.1 4	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b>	<b>0.9</b> 5	4
Patent ductus arteriosus	1.1 168	<b>0.0</b> 5	<b>0.0</b> 0	<b>0.0</b> 2	<b>2.1</b> 46	1.1 225	5
	46.8	69.3	0.0	33.2	96.4	50.6	
Pulmonary valve atresia and stenosis	46 12.8	1 <b>13.9</b>	0 <b>0.0</b>	0 <b>0.0</b>	14 <b>29.4</b>	62 <b>14.0</b>	6
Pyloric stenosis	83	1	0	0	20	105	
Rectal and large intestinal atresia/stenosis	<b>23.1</b> 13	<b>13.9</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>41.9</b>	<b>23.6</b> 15	
	3.6	13.9	0.0	0.0	2.1	3.4	

North Dakota Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

#### Maternal Race/Ethnicity American Asian or Pacific Indian or White Black Islander Alaska Native Non-Hispanic Non-Hispanic Defect Non-Hispanic Hispanic Total\*\* Non-Hispanic Notes Reduction deformity, lower limbs 6 0.0 0.0 0.0 4.2 1.4 1.1 Reduction deformity, upper limbs 3 0 0 0 0 3 0.0 0.0 0.0 **0.**7 0.8 0.0 Renal agenesis/hypoplasia 11 15 0.0 0.0 0.0 8.4 3.4 3.1 Spina bifida without anencephalus 25 18 0 0 0 0.0 0.0 0.0 5.0 14.7 5.6 Tetralogy of Fallot 19 26 5.3 0.0 0.0 0.0 5.9 14.7 Total anomalous pulmonary venous return 0 0 0 0 0.0 0.0 0.0 0.0 2.1 0.2 (TAPVR) Transposition of great arteries - All 21 0 22 0 0 0.0 0.0 0.0 2.1 5.0 5.9 Tricuspid valve atresia and stenosis 5 5 0.0 0.0 0.0 0.0 1.1 1.4 Trisomy 18 4 8 1.1 0.0 0.0 16.6 0.0 1.1 Ventricular septal defect 9 130 184 3 0 0 42 0.0 41.6 0.0 88.1 41.4 36.2 **Total Live Births** 35881 1733 602 44427 721 4770 **Total Male Live Births** 18331 416 762 245 2575 22680

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births

<sup>\*\*</sup>Total includes unknown race

# **North Dakota**

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)						
Defect	Less than 35	35+	Total**	Notes		
Down syndrome (Trisomy 21)	25 <b>6.3</b>	15 <b>33.2</b>	41 <b>9.2</b>			
Trisomy 13	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	8		
Trisomy 18	4 1.0	1 2.2	5 1.1	8		
Total Live Births	39847	4520	44427			

<sup>\*\*</sup>Total includes unknown maternal age

#### Notes

- 1.State uses ICD-9 code 745.60. .61, .69 for confirmed diagnosis. We cannot distinguish 745.487 CDC/BPA codes.
- 2. North Dakota Vital Statistics collects data using ICD-10 codes. Gastroschisis and Omphalocele cannot be distinguished.
- 3. The state uses ICD-9 codes and cannot distinguish between epispadias & hypospadias unless reported.
- 4.North Dakota Vital Statistics collects data using ICD-10 codes; Gastroschisis and Omphalocele cannot be distinguished. North Dakota Vital Statistics has started collected data using ICD-10 codes for Omphalocele from 2008 onwards in the birth certificates.
- 5.Infants less than 2500 grams birth weight are unable to be excluded.
- 6.Only ICD-9 code 746.01
- 7.State uses ICD-9 code 746.1 for confirmed diagnosis. We cannot distinguish 746.105 and 746.106 CDC/BPA codes.
- 8.North Dakota Vital Statistics implemented electronic registration of births starting in 2006. Underascertainment of confirmed trisomy cases are suspected in the new electronic birth certificate.
- 9.State uses ICD-9 code 745.4 for confirmed diagnosis. We cannot distinguish 745.487 and 745.498 CDC/BPA codes.

- -During the reporting period 2013, data from the Division of Medical Genetics at the University of North Dakota School of Medicine and Health Sciences were linked to the registry to enhance the reporting in the ND Birth Defects Monitoring System and includes data for births with defects for infants born in the calendar year 2010 from the Division of Medical Genetics program.
- -Fetal Death or 'birth resulting in stillbirth' means death prior to the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy. The death is indicated by the fact that after such expulsion or extraction the fetus does not breathe or show any evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles. North Dakota does not require reporting of this event before 20 weeks of gestation. Although collection is attempted, reporting is poor.
- -North Dakota Vital Statistics implemented electronic registration of births starting in 2006.
- -Statistical records of induced termination and spontaneous termination are filed. Defects are not recorded.
- -The North Dakota Birth Defects Monitoring System master registry is translated to ICD-9 using ICD-10 codes from fetal death, death and birth certificates.

Ohio Birth Defects Counts and Prevalence 2008 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Cleft lip with and without cleft palate		14 <b>5.6</b>	5 7.3	3 9.6	0 <b>0.0</b>	141 <b>9.5</b>	1
Cleft palate without cleft lip	94 <b>8.3</b>	19 7.7	3 4.4	2 <b>6.4</b>	0 <b>0.0</b>	118 <b>7.9</b>	1
Down syndrome (Trisomy 21)	126 11.1	27 <b>10.9</b>	8 11.6	3 <b>9.6</b>	1 46.3	165 <i>11.1</i>	2
Spina bifida without anencephalus	40 3.5	3 1.2	3 <b>4.4</b>	0 <b>0.0</b>	0 <b>0.0</b>	46 <b>3.1</b>	3
Trisomy 13	10 <b>0.9</b>	2 <b>0.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	12 <b>0.8</b>	2
Trisomy 18	15 <b>1.3</b>	8 <b>3.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	23 <b>1.5</b>	2
<b>Total Live Births</b>	113542	24818	6887	3129	216	148592	
<b>Total Male Live Births</b>	57955	12532	3482	1605	103	75677	

<sup>\*\*</sup>Total includes unknown race

Ohio Trisomy Counts and Prevalence by Maternal Age 2008 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35 years old	35 years old or older	Total	Notes			
Down syndrome (Trisomy 21)	96	69	165	2			
	7.3	39.6	11.1				
Trisomy 13	9	3	12	2			
	<b>0.</b> 7	1.7	0.8				
Trisomy 18	7	16	23	2			
	0.5	9.2	1.5				
Total Live Births	131185	17407	148592				

<sup>\*\*</sup>Total includes unknown maternal age

- Notes
  1.Data pulled on July 14, 2011.
  2.Data pulled on August 23, 2011.
  3.Data pulled on July 5, 2011.

# **General comments**

-Data is only available for the year 2008.

Oklahoma Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Amniotic bands	9	3	1	1	2	16	Tioles
	0.5	1.2	0.3	1.6	0.7	0.6	
Anencephalus	45 <b>2.6</b>	4 <b>1.6</b>	7 <b>2.0</b>	2 <b>3.3</b>	7 <b>2.3</b>	65 <b>2.4</b>	
Aniridia	6	0	1	0	0	8	
A 1d 1 : / : 1d 1 :	0.3	0.0	0.3	0.0	0.0	0.3	
Anophthalmia/microphthalmia	24 <b>1.4</b>	2 <b>0.8</b>	6 1.7	1 <b>1.6</b>	6 <b>2.0</b>	39 <b>1.4</b>	
Anotia/microtia	35	2	14	2	5	58	
Aortic valve stenosis	<b>2.0</b> 69	<b>0.8</b> 6	<b>4.0</b> 9	<b>3.3</b> 0	<b>1.7</b> 5	<b>2.2</b> 89	
	4.0	2.4	2.5	0.0	1.7	3.3	
Atrial septal defect	1244 <b>72.2</b>	203 <b>82.6</b>	171 <b>48.3</b>	17 <b>28.0</b>	256 <b>84.</b> 7	1903 <b>70.</b> 7	
Atrioventricular septal defect	88	15	10	0	15	128	
(endocardial cushion defect)	<b>5.1</b> 12	<b>6.1</b>	<b>2.8</b> 2	0.0	<b>5.0</b> 3	<b>4.8</b> 18	
Biliary atresia	<b>0.</b> 7	0.4	0.6	0 <b>0.0</b>	1.0	<b>0.</b> 7	
Bladder exstrophy	6	1	0	0	2	9	
Choanal atresia	<i>0.3</i> 30	2	<b>0.0</b> 3	<b>0.0</b> 1	<b>0.7</b> 4	<b>0.3</b> 40	
	1.7	0.8	0.8	1.6	1.3	1.5	
Cleft lip with and without cleft palate	147 <b>8.5</b>	16 <b>6.5</b>	17 <b>4.8</b>	4 <b>6.6</b>	29 <b>9.6</b>	214 <b>8.0</b>	
Cleft palate without cleft lip	256	19	30	6	47	358	
Coarctation of aorta	14.9	7.7	8.5	9.9	15.6	13.3	
Coarctation of aorta	95 <b>5.5</b>	15 <b>6.1</b>	14 <b>4.0</b>	2 <b>3.3</b>	17 <b>5.6</b>	144 <b>5.4</b>	
Common truncus	20	4	2	1	3	30	
Congenital cataract	1.2 38	<b>1.6</b> 6	<b>0.6</b>	<b>1.6</b> 0	<b>1.0</b> 3	<b>1.1</b> 49	
	2.2	2.4	0.3	0.0	1.0	1.8	
Congenital hip dislocation	77 <b>4.5</b>	5 <b>2.0</b>	15 <b>4.2</b>	4 <b>6.6</b>	10 <b>3.3</b>	112 <b>4.2</b>	
Diaphragmatic hernia	75	6	13	2	8	104	
D d (T-i 21)	<b>4.4</b> 203	2.4 24	<b>3.</b> 7 67	3.3	<b>2.6</b> 32	3.9 332	
Down syndrome (Trisomy 21)	11.8	9.8	18.9	6 <b>9.9</b>	10.6	12.3	
Ebstein anomaly	13	0	2	0	2	17	
Encephalocele	<b>0.8</b> 17	<b>0.0</b> 5	<b>0.6</b>	<b>0.0</b>	<b>0.7</b>	<b>0.6</b> 26	
•	1.0	2.0	0.3	1.6	0.3	1.0	
Epispadias	10 <b>0.6</b>	3 1.2	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	13 <b>0.5</b>	
Esophageal atresia/tracheoesophageal	53	8	8	1	10	80	
fistula Fetus or newborn affected by maternal	<b>3.1</b> 5	<b>3.3</b>	<b>2.3</b> 0	<b>1.6</b> 0	<b>3.3</b> 0	<b>3.0</b> 6	
alcohol use	0.3	0.4	0.0	0.0	0.0	0.2	
Gastroschisis	113	7 <b>2.8</b>	20	3 4.9	33 10.9	176 <b>6.5</b>	
Hirschsprung disease (congenital	<b>6.6</b> 30	6	<b>5.6</b> 2	1	5	44	
megacolon)	1.7	2.4	0.6	1.6	1.7	1.6	
Hydrocephalus without spina bifida	115 <b>6.</b> 7	16 <b>6.5</b>	17 <b>4.8</b>	1 <b>1.6</b>	21 7.0	171 <b>6.4</b>	
Hypoplastic left heart syndrome	43	2	4	1	9	60	
Hypospadias*	2.5 410	<b>0.8</b> 48	1.1 15	<b>1.6</b> 8	<b>3.0</b> 49	2.2 533	
	46.5	38.3	8.3	25.8	32.0	38.8	
Microcephalus	133 7.7	24 <b>9.8</b>	20 <b>5.6</b>	1 <b>1.6</b>	23 7. <b>6</b>	203 7.5	
Obstructive genitourinary defect	772	88	142	24	95	1124	
Omnhalagala	<b>44.8</b> 44	35.8	<b>40.1</b> 7	39.5	<b>31.4</b> 6	<b>41.8</b> 65	
Omphalocele	2.6	8 3.3	2.0	0 <b>0.0</b>	2.0	2.4	

Oklahoma Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total** Note	
Pulmonary valve atresia and stenosis	128	21	23	2	23	197	
	7.4	8.5	6.5	3.3	7.6	7.3	
Pulmonary valve atresia	17	3	3	0	3	26	
<b>5.1</b>	1.0	1.2	0.8	0.0	1.0	1.0	
Pyloric stenosis	769	42	131	8	138	1090	
	44.6	17.1	37.0	13.2	45.7	40.5	
Rectal and large intestinal atresia/stenosis		17	21	3 <b>4.9</b>	16	170	
Daduation deformative lever limbs	<b>6.5</b> 27	<b>6.9</b> 2	<b>5.9</b> 5	0	5.3 4	<b>6.3</b> 39	
Reduction deformity, lower limbs	1.6	0.8	3 1.4	0.0	1.3	1.4	
Reduction deformity, upper limbs	59	9	8	1	18	96	
Reduction deformity, upper minos	3.4	3.7	2.3	1.6	6.0	<b>3.6</b>	
Renal agenesis/hypoplasia	101	12	18	3	16	153	
Renar agenesis/ hypopiasia	5.9	4.9	5.1	4.9	5.3	5.7	
Spina bifida without anencephalus	87	6	12	0	9	116	
Spina offica without anoncepharas	5.1	2.4	3.4	0.0	3.0	4.3	
Tetralogy of Fallot	83	16	16	1	15	131	
63	4.8	6.5	4.5	1.6	5.0	4.9	
Total anomalous pulmonary venous return	1 22	4	5	0	9	40	
(TAPVR)	1.3	1.6	1.4	0.0	3.0	1.5	
Transposition of great arteries - All	62	8	7	1	11	89	
	3.6	3.3	2.0	1.6	3.6	3.3	
dextro-Transposition of great arteries	57	8	6	1	11	83	
(d-TGA)	3.3	3.3	1.7	1.6	3.6	3.1	
Tricuspid valve atresia and stenosis	21	3	5	0	2	31	
	1.2	1.2	1.4	0.0	0.7	1.2	
Tricuspid valve atresia	15	3	3	0	1	22	
m: 12	0.9	1.2	0.8	0.0	0.3	0.8	
Trisomy 13	20	4	2	0	5	31	
Trigomy 10	<b>1.2</b> 37	<b>1.6</b> 9	<b>0.6</b> 2	0.0	<b>1.7</b> 7	1.2 56	
Trisomy 18	2.1	3.7	<b>0.6</b>	1 <b>1.6</b>	2.3	2.1	
Ventricular septal defect	973	144	178	21	161	1485	
ventricular septar defect	56.5	58.6	50.3	34.6	53.3	55.2	
<b>Total Live Births</b>	172234	24580	35414	6075	30211	269052	
<b>Total Male Live Births</b>	88148	12524	18005	3095	15336	137367	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

Oklahoma

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age						
Defect	Less than 35	35 and greater	Total**	Notes		
Down syndrome (Trisomy 21)	188 <b>7.6</b>	143 <b>63.5</b>	332 <b>12.3</b>			
Trisomy 13	24 <b>1.0</b>	7 <b>3.1</b>	31 <b>1.2</b>			
Trisomy 18	39 <b>1.6</b>	17 7. <b>6</b>	56 <b>2.1</b>			
Total Live Births	246518	22513	269052			

<sup>\*\*</sup>Total includes unknown maternal age

<sup>-</sup>Oklahoma definition of stillbirth is baby born dead (without heart rate), at or after 20th gestational week; includes babies that died during labor.

Puerto Rico Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes		
Anencephalus	0	0	93	0	0	93	riotes		
Anophthalmia/microphthalmia	0	0	<b>4.1</b> 20	0	0	<b>4.1</b> 20	1		
Anotia/microtia	0	0	1.5 34 2.6	0	0	1.5 34 2.6	1		
Aortic valve stenosis	0	0	42 1.8	0	0	42 1.8			
Atrial septal defect	0	0	502 22.0	0	0	502 22.0	2		
Atrioventricular septal defect (endocardial cushion defect)	0	0	100 4.4	0	0	100 4.4	3		
Cleft lip with and without cleft palate	0	0	209 <b>9.2</b>	0	0	209 <b>9.2</b>			
Cleft palate without cleft lip	0	0	145 <b>6.4</b>	0	0	145 <b>6.4</b>			
Coarctation of aorta	0	0	247 10.8	0	0	247 10.8			
Common truncus	0	0	13 <b>0.6</b>	0	0	13 <b>0.6</b>			
Down syndrome (Trisomy 21)	0	0	324 14.2	0	0	324 14.2			
Ebstein anomaly	0	0	21 <b>0.9</b>	0	0	21 <b>0.9</b>			
Encephalocele	0	0	29 1.3	0	0	29 1.3			
Epispadias	0	0	6 0.3	0	0	6 <b>0.3</b>	4		
Gastroschisis	0	0	116 <b>5.1</b>	0	0	116 <b>5.1</b>	5		
Hypoplastic left heart syndrome	0	0	50 2.2	0	0	50 2.2			
Hypospadias*	0	0	307 33.3	0	0	307 33.3	4		
Omphalocele	0	0	57 <b>2.5</b>	0	0	57 <b>2.5</b>	5		
Patent ductus arteriosus	0	0	551 <b>24.1</b>	0	0	551 <b>24.1</b>	6		
Pulmonary valve atresia and stenosis	0	0	239 10.5	0	0	239 10.5			
Pulmonary valve atresia	0	0	22 1.0	0	0	22 1.0			
Reduction deformity, lower limbs	0	0	36 1.6	0	0	36 1.6			
Reduction deformity, upper limbs	0	0	81 3.5	0	0	81 3.5			
Spina bifida without anencephalus	0	0	109 <b>4.8</b>	0	0	109 <b>4.8</b>			
Tetralogy of Fallot	0	0	92 <b>4.0</b>	0	0	92 <b>4.0</b>			
Total anomalous pulmonary venous return (TAPVR)	1 0	0	15 <b>0.</b> 7	0	0	15 <b>0.</b> 7			
Transposition of great arteries - All	0	0	64 2.8	0	0	64 2.8			
dextro-Transposition of great arteries (d-TGA)	0	0	54 2.4	0	0	54 2.4			
Tricuspid valve atresia and stenosis	0	0	2.4 29 1.3	0	0	2.4 29 1.3	7		
Trisomy 13	0	0	30 1.3	0	0	30 1.3			
Trisomy 18	0	0	83 3.6	0	0	83 3.6			
Ventricular septal defect	0	0	554 24.3	0	0	554 24.3	8		

**Puerto Rico** Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Total Live Births	0	0	228267	0	0	228267	
<b>Total Male Live Births</b>	0	0	92279	0	0	92279	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

**Puerto Rico** Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

		Age		
Defect	Less than 35	35 and greater	Total**	Notes
Down syndrome (Trisomy 21)	190 <b>9.1</b>	134 <b>70.4</b>	324 <b>14.2</b>	
Trisomy 13	19 <b>0.9</b>	11 <b>5.8</b>	30 1.3	
Trisomy 18	50 <b>2.4</b>	33 <b>17.3</b>	83 <b>3.6</b>	
<b>Total Live Births</b>	209158	19038	228267	

<sup>\*\*</sup>Total includes unknown maternal age

- 1.Data only available 2008-2010. 2.Excludes PFO.
- 3.Only includes AV Canal.
- 4.Data only available 2007-2010.

  5.We used clinical diagnosis to distinguish the two conditions.
- 6.Unable to exclude infants with defect last noted at less than 6 weeks of age.
- 7.Excludes 746.106 and 746.105.
- 8. Excludes probable cases. We can't distinguish inlet VSD from other VSD. However we exclude inlet/posterior type VSD in the presence of AV Canal.

- -Probable/possible diagnoses were not included. -The coding system used was ICD 9 CM.
- -We include stillbirths and terminations (no gestational age cut off) in our counts.

Rhode Island Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes		
Amniotic bands	0	0	3	0	0	3	Tioles		
Ananaanhalisa	<b>0.0</b> 3	<b>0.0</b> 0	<b>2.5</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.5</b> 3			
Anencephalus	0.8	0.0	0.0	0.0	0.0	0.5			
Anophthalmia/microphthalmia	1 <b>0.3</b>	1 2.0	1 <b>0.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.5</b>			
Anotia/microtia	1 <b>0.3</b>	0 <b>0.0</b>	4 <b>3.4</b>	0 <b>0.0</b>	1 <b>18.6</b>	6 <b>1.0</b>			
Aortic valve stenosis	4 1.1	1 2.0	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	5 <b>0.9</b>			
Atrial septal defect	117 32.7	26 <b>52.6</b>	45 37.8	4 15.8	3 55.9	198 <b>34.4</b>			
Atrioventricular septal defect	11	1	1	0	0	13			
(endocardial cushion defect) Biliary atresia	<b>3.1</b>	<b>2.0</b>	<b>0.8</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	2.3 3			
	0.3	2.0	0.0	0.0	0.0	0.5			
Bladder exstrophy	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.2</b>			
Choanal atresia	2	1	0	0	0	3			
Cleft lip with and without cleft palate	<b>0.6</b> 19	2.0	0.0 11	0.0 2	0.0	0.5 35			
Cleft palate without cleft lip	<b>5.3</b> 24	<b>4.0</b>	<b>9.2</b> 7	<b>7.9</b> 3	<b>0.0</b>	<b>6.1</b> 36			
	6.7	2.0	5.9	11.8	18.6	6.3			
Coarctation of aorta	4 1.1	2 <b>4.0</b>	4 3.4	1 <b>3.9</b>	0 <b>0.0</b>	11 <b>1.9</b>			
Common truncus	0 <b>0.0</b>	1 <b>2.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.2</b>			
Congenital cataract	1 <b>0.3</b>	1 2.0	1 <b>0.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.5</b>			
Congenital hip dislocation	35 9.8	4 8.1	7 5.9	0.0 0.0	0.0 0.0	46 <b>8.0</b>			
Diaphragmatic hernia	10 2.8	1 2.0	3.7 2.5	1 3.9	0.0 0.0	16 2.8			
Down syndrome (Trisomy 21)	48	5	16	2	0	84			
Ebstein anomaly	13.4 3	10.1 0	13.4 0	7.9 0	<b>0.0</b> 0	14.6 3			
Encephalocele	<b>0.8</b> 1	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	0.0	<b>0.5</b>			
	0.3	0.0	0.0	0.0	0.0	0.2			
Epispadias	8 2.2	1 2.0	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	9 <b>1.6</b>			
Esophageal atresia/tracheoesophageal fistula	9 <b>2.5</b>	1 2.0	4 3.4	0 <b>0.0</b>	0 <b>0.0</b>	15 <b>2.6</b>			
Fetus or newborn affected by maternal	5	4	4	0	0	15			
alcohol use Gastroschisis	<b>1.4</b> 11	<b>8.1</b> 4	<b>3.4</b> 8	<b>0.0</b> 1	<b>0.0</b> 0	<b>2.6</b> 24			
	3.1	8.1	6.7	3.9	0.0	4.2			
Hirschsprung disease (congenital megacolon)	2 <b>0.6</b>	0 <b>0.0</b>	3 2.5	0 <b>0.0</b>	0 <b>0.0</b>	6 <b>1.0</b>			
Hydrocephalus without spina bifida	15 <b>4.2</b>	4 <b>8.</b> 1	5 <b>4.2</b>	2 7.9	1 <b>18.6</b>	29 <b>5.0</b>			
Hypoplastic left heart syndrome	4 1.1	1 2.0	1 <b>0.8</b>	2 7.9	0 <b>0.0</b>	8 1.4			
Hypospadias*	143	22	46	4	1	221			
Microcephalus	77.6 11	87.3 2	75.0	32.3 3	36.8 0	75.1 20			
Obstructive genitourinary defect	<b>3.1</b> 99	<b>4.0</b> 22	<b>3.4</b> 37	<b>11.8</b> 7	<b>0.0</b>	<b>3.5</b> 172			
	27.7 6	<b>44.5</b> 2	<b>31.0</b> 3	<b>27.6</b> 0	<b>18.6</b> 0	<b>29.9</b> 11			
Omphalocele	1.7	4.0	2.5	<b>0.0</b>	0.0	1.9			
Patent ductus arteriosus	108 3 <b>0.2</b>	23 <b>46.6</b>	44 <b>36.9</b>	7 <b>27.6</b>	2 37.2	190 <b>33.0</b>	1		

**Rhode Island** Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal Ra	ce/Ethnicity				
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Pulmonary valve atresia and stenosis	19	3	10	1	1	35	
	5.3	6.1	8.4	3.9	18.6	6.1	
Pulmonary valve atresia	6	0	2	0	1	9	
	1.7	0.0	1.7	0.0	18.6	1.6	
Pyloric stenosis	16	3	5	0	1	27	
	4.5	6.1	4.2	0.0	18.6	4.7	
Rectal and large intestinal atresia/stenosis		4	5	1	0	22	
	3.4	8.1	4.2	3.9	0.0	3.8	
Reduction deformity, lower limbs	7	0	3	0	0	10	
	2.0	0.0	2.5	0.0	0.0	1.7	
Reduction deformity, upper limbs	7	0	1	0	0	9	
	2.0	0.0	0.8	0.0	0.0	1.6	
Renal agenesis/hypoplasia	3	1	1	0	0	6	
0: 1:01 :4	0.8	2.0	0.8	0.0	0.0	1.0	
Spina bifida without anencephalus	8 2.2	1 2.0	5 <b>4.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	15	
T-41	9	2.0			0.0	<b>2.6</b> 19	
Tetralogy of Fallot	2.5	4.0	6 <b>5.0</b>	0 <b>0.0</b>	<b>0</b> .0	3.3	
Total anomalous pulmonary venous return		0	3	0.0	0.0	4	
(TAPVR)	0.3	0.0	2.5	0.0	0.0	<b>0.</b> 7	
Transposition of great arteries - All	9	1	4	2	0.0	17	
Transposition of great afteries - All	2.5	2.0	3.4	7.9	0.0	3.0	
dextro-Transposition of great arteries	4	1	3	1	0.0	9	
(d-TGA)	1.1	2.0	2.5	3.9	0.0	1.6	
Tricuspid valve atresia and stenosis	0	0	1	0	1	2	
Theuspia varve attesta and stemosis	0.0	0.0	0.8	0.0	18.6	0.3	
Tricuspid valve atresia	0.0	0.0	1	0	1	2	
Titodspid varve diresid	0.0	0.0	0.8	0.0	18.6	0.3	
Trisomy 13	2	2	3	1	0	10	
111001119 13	0.6	4.0	2.5	3.9	0.0	1.7	
Trisomy 18	11	1	4	0	0	19	
<b>y</b> •	3.1	2.0	3.4	0.0	0.0	3.3	
Ventricular septal defect	131	15	48	11	1	210	
1	36.6	30.4	40.3	43.4	18.6	36.5	
Total Live Births	35791	4940	11917	2534	537	57518	
<b>Total Male Live Births</b>	18416	2521	6134	1238	272	29429	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

**Rhode Island** Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age						
Defect	Less than 35	35 and greater	Total**	Notes		
Down syndrome (Trisomy 21)	35 7.4	40 <b>40.0</b>	84 <b>14.6</b>			
Trisomy 13	4 <b>0.8</b>	5 <b>5.0</b>	10 1.7			
Trisomy 18	8 1.7	9 <b>9.0</b>	19 <b>3.3</b>			
Total Live Births	47524	9988	57518			

<sup>\*\*</sup>Total includes unknown maternal age

1.Excludes PDA less than 36 weeks of gestation.

- -Maternal race/ethnicity and age numbers for 2009 prenatally ascertained cases are not available.
  -Prenatally ascertained and post-newborn inpatient discharge cases were collected beginning in 2009.
  -Total live births by race has been revised for 2008-2009.

South Carolina Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity							
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Anencephalus	33	21	14	0	0	70		
Aniridia	1.9	<b>2.1</b> 2	<b>4.8</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>2.3</b> 5		
Aniridia	3 <b>0.2</b>	0.2	0. <i>0</i>	<b>0.0</b>	<b>0.0</b>	0.2		
Anophthalmia/microphthalmia	7	4	1	0	0	12		
Anotia/microtia	0.4	0.4	<b>0.3</b> 0	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.4</b> 13		
Anoua/microua	6 <b>0.4</b>	6 <b>0.6</b>	<b>0.0</b>	2.0	<b>0</b> .0	0.4		
Aortic valve stenosis	12	6	5	1	0	26		
4.11	0.7	0.6	1.7	2.0	0.0	0.8	•	
Atrial septal defect	226 <b>22.0</b>	152 <b>24.</b> 7	53 <b>28.</b> 7	7 <b>23.6</b>	0 <b>0.0</b>	445 <b>23.4</b>	1	
Atrioventricular septal defect	77	58	10	0	0	147		
(endocardial cushion defect)	4.5	5.8	3.4	0.0	0.0	4.7		
Biliary atresia	6 <b>0.4</b>	7 <b>0.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	13 <b>0.4</b>		
Bladder exstrophy	0.4	2	0.0	0.0	0	2		
	0.0	0.2	0.0	0.0	0.0	0.1		
Choanal atresia	11 <b>0.6</b>	6 <b>0.6</b>	3 <b>1.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	22 <b>0.</b> 7		
Cleft lip with and without cleft palate	147	57	28	8	2	250		
	8.6	<b>5.</b> 7	9.6	15.9	16.2	8.1		
Cleft palate without cleft lip	78	49	12 <b>4.1</b>	2 <b>4.0</b>	0 <b>0.0</b>	143 <b>4.6</b>		
Coarctation of aorta	<b>4.6</b> 91	<b>4.9</b> 33	10	4. <i>0</i> 2	0.0	4. <b>6</b> 137		
	5.3	3.3	3.4	4.0	0.0	4.4		
Common truncus	13	3	1	0	1	18		
Congenital cataract	<b>0.8</b> 10	<i>0.3</i> 4	<b>0.3</b> 3	<b>0.0</b> 0	<b>8.1</b> 0	<b>0.6</b> 17		
	0.6	0.4	1.0	0.0	0.0	0.5		
Congenital hip dislocation	60	13	16	2	0	91		
Diaphragmatic hernia	<b>3.5</b> 42	1.3 15	5.5 13	<b>4.0</b> 0	<b>0.0</b> 0	<b>2.9</b> 71		
Diaphragmatic norma	2.5	1.5	4.5	0.0	0.0	2.3		
Down syndrome (Trisomy 21)	109	52	21	4	0	189	2	
Ebstein anomaly	10.6 10	<b>8.</b> 7 4	12.4 1	12.8 2	<b>0.0</b> 0	10.3 17		
Eostem anomary	0.6	0.4	0.3	4.0	0.0	0.5		
Encephalocele	18	10	9	2	0	39		
Epispadias	1.1 4	<b>1.0</b>	<b>3.1</b> 0	<b>4.0</b> 0	<b>0.0</b> 0	1.3 5	3	
Epispadias	1.2	0.5	0.0	0.0	0.0	0.8	3	
Esophageal atresia/tracheoesophageal	10	7	2	0	0	19		
fistula	0.6	0.7	<b>0.</b> 7	0.0	0.0	0.6		
Gastroschisis	24 <b>1.4</b>	7 <b>0.</b> 7	5 <b>1.7</b>	1 <b>2.0</b>	0 <b>0.0</b>	38 1.2		
Hirschsprung disease (congenital	25	14	1	0	0	40		
megacolon)	1.5	1.4	0.3	0.0	0.0	1.3		
Hydrocephalus without spina bifida	97 <b>5.</b> 7	62 <b>6.2</b>	18 <b>6.2</b>	3 <b>6.0</b>	0 <b>0.0</b>	180 <b>5.8</b>		
Hypoplastic left heart syndrome	42	31	10	1	0.0	84		
	2.5	3.1	3.4	2.0	0.0	2.7		
Microcephalus	46	55	22	3	0	129		
Obstructive genitourinary defect	<b>2.7</b> 110	<b>5.5</b> 51	<b>7.6</b> 27	<b>6.0</b> 1	<b>0.0</b> 0	<b>4.2</b> 194		
	6.5	5.1	9.3	2.0	0.0	6.3		
Omphalocele	11	8	0	0	0	19		
Patent ductus arteriosus	<b>0.6</b> 196	<b>0.8</b> 179	<b>0.0</b> 51	<b>0.0</b> 6	<b>0.0</b>	<b>0.6</b> 441	4	
datas arteriosas	19.1	29.0	27.7	20.3	14.0	23.2	•	

South Carolina Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Pulmonary valve atresia and stenosis	93	63	18	1	1	181	
	5.5	6.3	6.2	2.0	8.1	5.8	
Pulmonary valve atresia	20	16	5	0	0	42	
•	1.2	1.6	1.7	0.0	0.0	1.4	
Pyloric stenosis	70	25	20	1	1	119	5
•	6.8	4.1	10.8	3.4	14.0	6.3	
Rectal and large intestinal atresia/stenosis	42	16	2	2	1	63	
Ç	2.5	1.6	0.7	4.0	8.1	2.0	
Reduction deformity, lower limbs	39	26	5	0	0	70	
•	2.3	2.6	1.7	0.0	0.0	2.3	
Reduction deformity, upper limbs	46	28	15	0	1	91	
• • • •	2.7	2.8	5.2	0.0	8.1	2.9	
Renal agenesis/hypoplasia	51	33	9	1	0	94	
	3.0	3.3	3.1	2.0	0.0	3.0	
Spina bifida without anencephalus	64	18	7	2	0	91	
	3.8	1.8	2.4	4.0	0.0	2.9	
Tetralogy of Fallot	63	53	12	1	0	131	
	<b>3.</b> 7	5.3	4.1	2.0	0.0	4.2	
Transposition of great arteries - All	84	38	8	1	1	136	
	4.9	3.8	2.8	2.0	8.1	4.4	
dextro-Transposition of great arteries	45	15	3	0	1	66	
(d-TGA)	2.6	1.5	1.0	0.0	8.1	2.1	
Tricuspid valve atresia and stenosis	10	10	5	1	0	26	
•	0.6	1.0	1.7	2.0	0.0	0.8	
Trisomy 13	8	10	1	0	0	20	6
·	0.8	1.7	0.6	0.0	0.0	1.1	
Trisomy 18	22	13	6	0	0	41	7
•	2.1	2.2	3.5	0.0	0.0	2.2	
Ventricular septal defect	534	319	146	13	2	1024	
	31.3	31.8	50.2	25.8	16.2	33.0	
<b>Total Live Births</b>	170368	100370	29088	5038	1237	310007	
<b>Total Male Live Births</b>	86927	50658	14931	2520	656	157707	

<sup>\*\*</sup>Total includes unknown race

# **South Carolina**

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)						
Defect	Less than 35	35+	Total	Notes		
Down syndrome (Trisomy 21)	100	89	189	2		
	6.1	44.8	10.3			
Trisomy 13	16	4	20	6		
	1.0	2.0	1.1			
Trisomy 18	22	19	41	7		
	1.3	9.6	2.2			
Total Live Births (2008-2010)	163862	19864	183735			

<sup>\*\*</sup>Total includes unknown maternal age

# Notes

- 1.Atrial Septal Defect was dropped beginning in 2009. Prevalence reflects live birth data for the years 2006-2008
  2.Down Syndrome was collected beginning in 2008. Prevalence reflects live birth data for the years 2008-2010
  3.Epispadias data only available for 2010. Prevalence reflects live birth data for the year 2010
  4.Patent Ductus Arteriosus was dropped beginning in 2009. Prevalence reflects live birth data for the years 2006-2008
  5.Pyloric Stenosis was dropped beginning in 2009. Prevalence reflects live birth data for the years 2006-2008
  6.Triconsis was dropped beginning in 2009. Prevalence reflects live birth data for the years 2006-2008
  6.Triconsis was dropped beginning in 2009. Prevalence reflects live birth data for the years 2008-2008

- 6.Trisomy 13 was collected beginning in 2008. Prevalence reflects live birth data for the years 2008-2010 7.Trisomy 18 was collected beginning in 2008. Prevalence reflects live birth data for the years 2008-2010

Tennessee Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity	Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes					
Anencephalus	28	8 <b>0.9</b>	7	1 1.2	0 <b>0.0</b>	45						
Aniridia	<b>1.0</b> 7	0.9	<b>1.8</b>	0	0.0	1.1 8						
	0.2	0.0	0.3	0.0	0.0	0.2						
Anophthalmia/microphthalmia	26 <b>0.9</b>	15 <b>1.7</b>	3 <b>0.8</b>	1 1.2	0 <b>0.0</b>	46 <b>1.1</b>						
Anotia/microtia	19	3	7	1	0	30						
Aortic valve stenosis	<b>0.</b> 7 68	<b>0.3</b> 3	<b>1.8</b> 7	1.2 0	0.0	<b>0.</b> 7 79						
Aortic varve stellosis	2.4	0.3	1.8	0.0	0.0	1.9						
Atrial septal defect	2801 <b>99.8</b>	1370 <b>157.5</b>	337 <b>87.0</b>	50 <b>61.2</b>	1 <b>15.6</b>	4574 <b>109.5</b>						
Atrioventricular septal defect	118	36	11	1	0	166	1					
(endocardial cushion defect)	4.2	4.1	2.8	1.2	0.0	4.0						
Biliary atresia	20 <b>0.</b> 7	5 <b>0.6</b>	5 <b>1.3</b>	3 3.7	0 <b>0.0</b>	33 <b>0.8</b>						
Bladder exstrophy	17	4	0	0	0	21						
Choanal atresia	<b>0.6</b> 57	<b>0.5</b> 9	<b>0.0</b> 4	<b>0.0</b> 0	<b>0.0</b>	<b>0.5</b> 71						
Choanai aucsia	2.0	1.0	1.0	0.0	15.6	1.7						
Cleft lip with and without cleft palate	351	57	35	1 1.2	2 31.2	451						
Cleft palate without cleft lip	12.5 252	<b>6.6</b> 50	<b>9.0</b> 22	6	1	<b>10.8</b> 331						
	9.0	5.7	5.7	7.3	15.6	7.9						
Coarctation of aorta	202 7.2	51 <b>5.9</b>	32 <b>8.3</b>	1 1.2	0 <b>0.0</b>	287 <b>6.9</b>						
Common truncus	32	5	3	1	0	41						
Congenital cataract	<b>1.1</b> 71	<b>0.6</b> 22	<b>0.8</b> 2	1.2 4	<b>0.0</b> 0	<b>1.0</b> 99						
	2.5	2.5	0.5	4.9	0.0	2.4						
Congenital hip dislocation	255 <b>9.1</b>	47 <b>5.4</b>	32 <b>8.3</b>	4 <b>4.9</b>	0 <b>0.0</b>	338 <b>8.1</b>						
Diaphragmatic hernia	117	39	17	5	0	178						
D 1 (T : 21)	4.2	4.5	4.4	6.1	0.0	4.3						
Down syndrome (Trisomy 21)	393 <b>14.0</b>	116 <b>13.3</b>	64 <b>16.5</b>	10 12.2	0 <b>0.0</b>	586 <b>14.0</b>						
Ebstein anomaly	28	8	4	2	0	42						
Encephalocele	<b>1.0</b> 36	<b>0.9</b> 11	<b>1.0</b> 10	<b>2.4</b> 0	0.0	<b>1.0</b> 57						
	1.3	1.3	2.6	0.0	0.0	1.4						
Epispadias	47 <b>1. 7</b>	12 <b>1.4</b>	3 <b>0.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	62 <b>1.5</b>						
Esophageal atresia/tracheoesophageal	77	15	12	0	0	104						
fistula	2.7	1.7	3.1	0.0	0.0	2.5						
Fetus or newborn affected by maternal alcohol use	52 <b>1.9</b>	31 <b>3.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	83 <b>2.0</b>						
Gastroschisis	190	25	19	3	0	237	2					
Hirschsprung disease (congenital	<b>6.8</b> 77	<b>2.9</b> 43	<b>4.9</b> 6	3.7 0	<b>0.0</b>	5.7 128						
megacolon)	2.7	4.9	1.5	0.0	15.6	3.1						
Hydrocephalus without spina bifida	199 <b>7.1</b>	83 <b>9.5</b>	40 <b>10.3</b>	4 <b>4.9</b>	0 <b>0.0</b>	327 7.8						
Hypoplastic left heart syndrome	104	33	16	0	0	154						
Hypospadias*	<b>3.7</b> 1684	<b>3.8</b> 466	<b>4.1</b> 69	<b>0.0</b> 24	<b>0.0</b> 2	3.7 2254						
	117.0	105.0	34.9	57.5	64.5	105.4						
Microcephalus	318	110	52	2	0	486						
Obstructive genitourinary defect	<b>11.3</b> 999	<b>12.6</b> 185	<b>13.4</b> 96	<b>2.4</b> 30	<b>0.0</b> 0	11.6 1314						
	35.6	21.3	24.8	36.7	0.0	31.4						
Omphalocele	74 <b>2.6</b>	29 <b>3.3</b>	9 <b>2.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	112 <b>2.</b> 7	3					
Patent ductus arteriosus	1667	716	235	38	2	2663	4					
	59.4	82.3	<b>60.</b> 7	46.5	31.2	63.7						

Tennessee Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

#### Maternal Race/Ethnicity American Asian or Pacific Indian or White Black Islander Alaska Native Non-Hispanic Defect Non-Hispanic Non-Hispanic Hispanic Total\*\* Non-Hispanic Notes Pulmonary valve atresia and stenosis 26 405 9.9 10.3 9.8 31.2 9.7 6.7 Pulmonary valve atresia 45 16 2 0 71 2.4 0.0 1.6 1.8 1.8 **1.**7 1772 Pyloric stenosis 1347 221 185 12 31.2 25.4 14.7 42.4 48.0 47.8 Rectal and large intestinal atresia/stenosis 47 180 25 256 1.2 5.4 6.5 15.6 6.1 6.4 Reduction deformity, lower limbs 57 23 89 2.0 2.6 1.5 0.0 2.1 Reduction deformity, upper limbs 19 95 60 14 2.4 0.0 2.2 2.3 2.1 3.6 Renal agenesis/hypoplasia 145 54 22 4 225 0 6.2 **5.**7 4.9 0.0 5.4 5.2 Spina bifida without anencephalus 113 26 23 165 3.0 5.9 3.7 0.0 3.9 4.0 Tetralogy of Fallot 185 49 21 258 5.6 5.4 **3.**7 0.0 6.2 6.6 242 **5.8** Transposition of great arteries - All 5 165 47 24 4 0 4.9 5.9 0.0 5.4 6.2 67 17 95 dextro-Transposition of great arteries **3.**7 2.3 (d-TGA) 2.4 2.0 2.1 0.0 Tricuspid valve atresia and stenosis 43 52 6 0.7 1.5 0.5 0.0 0.0 1.2 Trisomy 13 17 12 0 35 0.6 1.4 $\theta.8$ 1.2 0.0 0.8 Trisomy 18 14 51 10 76 1.2 0.0 1.8 1.6 2.6 1.8 Ventricular septal defect 1348 405 195 1983 25 50.4 30.6 31.2 48.0 46.6 47.5 417903 **Total Live Births** 280780 86972 38725 8168 642 143899 44382 19791 4177 310 213856 **Total Male Live Births**

\*\*Total includes unknown race

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births

**Tennessee** Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)							
Defect	Less than 35	35+	Total	Notes			
Down syndrome (Trisomy 21)	349 <b>9.3</b>	237 <b>55.2</b>	586 <b>14.0</b>				
Trisomy 13	28 <b>0.</b> 7	7 <b>1.6</b>	35 <b>0.8</b>				
Trisomy 18	48 1.3	28 <b>6.5</b>	76 <b>1.8</b>				
<b>Total Live Births</b>	374846	42915	417903				

<sup>\*\*</sup>Total includes unknown maternal age

- 1.Tennessee does not use the new CDC/BPA codes and cannot distinguish 745.487 from other VSD.
- 2.ICD-9 Procedure 54.71
- 3.ICD-9 Procedure Code not equal to 54.71

- 4.Birthweight equal to 2500 grams.

  5.Tennessee does not use the new CDC/BPA codes: information includes the entire range.

  6.Tennessee does not use the new CDC/BPA codes and cases with 746.106 are included within this category 7.Includes probable cases. Tennessee does not use the new CDC/BPA codes and cannot distinguish 745.487.

Texas Birth Defects Counts and Prevalence 2006-2009 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Amniotic bands	47	20	51	4	1	124		
Anencephalus	<b>0.9</b> 110	1.1 35	<b>0.6</b> 254	<b>0.</b> 7 8	<b>3.4</b> 0	<b>0.8</b> 417		
Allencepharus	2.0	1.9	3.1	1.3	0.0	2.6		
Aniridia	6	2	7	1	0	16		
Anophthalmia/microphthalmia	<b>0.1</b> 168	<b>0.1</b> 50	<b>0.1</b> 284	<b>0.2</b> 14	2	<b>0.1</b> 521		
Anophthainna/microphthainna	3.0	2.7	3.5	2.4	6.9	3.2 3.2		
Anotia/microtia	104	30	397	23	3	559		
A	1.9	1.6	4.9	3.9	<b>10.3</b>	3.5		
Aortic valve stenosis	142 <b>2.6</b>	32 1.7	195 <b>2.4</b>	8 1.3	3.4	384 <b>2.4</b>		
Atrial septal defect	3520	1286	5246	303	16	10437		
	63.8	70.1	65.0	50.9	54.8	64.7		
Atrioventricular septal defect (endocardial cushion defect)	285 <b>5.2</b>	93 <b>5.1</b>	325 <b>4.0</b>	13 2.2	1 <b>3.4</b>	720 <b>4.5</b>		
Biliary atresia	36	11	65	7	2	122		
	0.7	0.6	0.8	1.2	6.9	0.8		
Bladder exstrophy	15	2 <b>0.1</b>	8	1 <b>0.2</b>	0 <b>0.0</b>	26		
Choanal atresia	<b>0.3</b> 86	23	<b>0.1</b> 95	0.2 7	0.0	<b>0.2</b> 212		
Chountal directa	1.6	1.3	1.2	1.2	0.0	1.3		
Cleft lip with and without cleft palate	606	126	898	58_	3	1701		
Claff malata without alaft lim	11.0 368	<b>6.9</b> 92	<b>11.1</b> 477	9.7 34	10.3 0	1 <b>0.5</b> 977		
Cleft palate without cleft lip	6.7	5. <b>0</b>	5.9	5.7	0.0	6.1		
Coarctation of aorta	314	67	426	20	3	836		
~	5.7	3.7	5.3	3.4	10.3	5.2		
Common truncus	42 <b>0.8</b>	12 <b>0.</b> 7	65 <b>0.8</b>	4 <b>0.</b> 7	0 <b>0.0</b>	123 <b>0.8</b>		
Congenital cataract	117	44	148	7	0.0	320		
	2.1	2.4	1.8	1.2	0.0	2.0		
Congenital hip dislocation	266 <b>4.8</b>	43 <b>2.3</b>	352 <b>4.4</b>	33 <b>5.5</b>	1 3.4	702 <b>4.4</b>		
Diaphragmatic hernia	165	41	244	12	1	466		
	3.0	2.2	3.0	2.0	3.4	2.9		
Down syndrome (Trisomy 21)	703	182	1232	67	3	2209		
Ebstein anomaly	12.7 36	<b>9.9</b> 4	<b>15.3</b> 55	11.2 6	10.3 0	13.7 101		
Eostem anomary	<b>0.</b> 7	0.2	<b>0.</b> 7	1.0	0.0	0.6		
Encephalocele	38	18	99	3	0	163		
r	0.7	1.0	1.2	0.5	0.0	1.0		
Epispadias	65 1.2	23 1.3	63 <b>0.8</b>	6 <b>1.0</b>	0 <b>0.0</b>	157 <b>1.0</b>		
Esophageal atresia/tracheoesophageal	130	24	169	10	2	338		
fistula	2.4	1.3	2.1	1.7	6.9	2.1		
Fetus or newborn affected by maternal alcohol use	12 <b>0.2</b>	7 <b>0.4</b>	11 <b>0.1</b>	1 <b>0.2</b>	0 <b>0.0</b>	31 <b>0.2</b>		
Gastroschisis	331	78	525	14	1	953		
	6.0	4.3	6.5	2.4	3.4	5.9		
Hirschsprung disease (congenital	99	46	66	12	2	228		
megacolon) Hydrocephalus without spina bifida	1.8 398	2.5 124	<b>0.8</b> 627	<b>2.0</b> 17	<b>6.9</b> 2	1.4 1176		
Trydrocepharus without spina offica	7.2	6.8	7.8	2.9	6.9	7.3		
Hypoplastic left heart syndrome	128	47	159	6	1	342		
Hypognodios*	2.3 2344	2.6	2.0	1.0	3.4	<b>2.1</b> 4732		
Hypospadias*	82.8	623 <b>66.6</b>	1572 <b>38.2</b>	157 <b>51.5</b>	11 72.9	4/32 <b>57.4</b>		
Microcephalus	527	276	979	59	7	1862		
	9.6	15.0	12.1	9.9	24.0	11.5		
Obstructive genitourinary defect	2589 <b>46.9</b>	591 <b>32.2</b>	3905 <b>48.4</b>	285 <b>47.8</b>	13 <b>44.6</b>	7434 <b>46.1</b>		
Omphalocele	105	45	166	9	2	335		
	1.9	2.5	2.1	1.5	6.9	2.1		

**Texas** Birth Defects Counts and Prevalence 2006-2009 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Patent ductus arteriosus	3010	983	5097	303	12	9468	1	
	54.6	53.6	63.2	50.9	41.1	<b>58.</b> 7		
Pulmonary valve atresia and stenosis	493	199	899	34	4	1635		
	8.9	10.9	11.1	<b>5.</b> 7	13.7	10.1		
Pulmonary valve atresia	77	24	135	4	0	242		
	1.4	1.3	1.7	0.7	0.0	1.5		
Pyloric stenosis	1234	158	1809	24	5	3241		
	22.4	8.6	22.4	4.0	17.1	20.1		
Rectal and large intestinal atresia/stenosis		72	463	26	3	864		
	5.2	3.9	<b>5.</b> 7	4.4	10.3	5.4		
Reduction deformity, lower limbs	117	49	144	6	0	318		
	2.1	2.7	1.8	1.0	0.0	2.0		
Reduction deformity, upper limbs	243	76	322	18	5	666		
	4.4	4.1	4.0	3.0	17.1	4.1		
Renal agenesis/hypoplasia	334	106	511	26	3	987		
	6.1	5.8	6.3	4.4	10.3	6.1		
Spina bifida without anencephalus	191	47	336	5	1	585		
	3.5	2.6	4.2	0.8	3.4	3.6		
Tetralogy of Fallot	220	89	287	31	2	638		
	4.0	4.9	3.6	5.2	6.9	4.0		
Total anomalous pulmonary venous return	172	17	184	8	1	284		
(TAPVR)	1.3	0.9	2.3	1.3	3.4	1.8		
Transposition of great arteries - All	234	52	281	24	1	593	2	
	4.2	2.8	3.5	4.0	3.4	3.7		
dextro-Transposition of great arteries	217	55	268	23	1	566		
(d-TGA)	3.9	3.0	3.3	3.9	3.4	3.5		
Tricuspid valve atresia and stenosis	94	45	155	10	0	307		
	1.7	2.5	1.9	1.7	0.0	1.9		
Tricuspid valve atresia	44	18	58	4	0	125		
	0.8	1.0	<b>0.</b> 7	0.7	0.0	0.8		
Trisomy 13	63	23	94	10	0	191		
	1.1	1.3	1.2	1.7	0.0	1.2		
Trisomy 18	147	49	223	22	0	448		
	2.7	2.7	2.8	<b>3.</b> 7	0.0	2.8		
Ventricular septal defect	3130	868	5723	292	15	10084	3	
	56.8	47.3	71.0	49.0	51.4	62.5		
Total Live Births	551516	183402	806505	59568	2918	1613603		
<b>Total Male Live Births</b>	283019	93563	411108	30498	1508	824643		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Texas
Trisomy Counts and Prevalence by Maternal Age 2006-2009 (Prevalence per 10,000 Live Births)

Age								
Defect	Less than 35	35 and greater	Total**	Notes				
Down syndrome (Trisomy 21)	1249 <b>8.8</b>	960 <b>51.1</b>	2209 <b>13.</b> 7					
Trisomy 13	136 <b>1.0</b>	55 <b>2.9</b>	191 <b>1.2</b>					
Trisomy 18	241 <b>1.</b> 7	207 11. <b>0</b>	448 <b>2.8</b>					
<b>Total Live Births</b>	1425617	187892	1613603					

<sup>\*\*</sup>Total includes unknown maternal age

Lin Texas, coding of patent ductus arteriosus (PDA) is based on the following criteria: infant must be greater than 36 weeks gestation and less than 12 weeks of age at diagnosis and not on prostaglandin. Also, PDA is coded only if there is another reportable defect present, or if there was a medical/surgical intervention for this problem.

2. Transposition of the great arteries: As Texas does not use the new CDC BPA codes and the exclusion criteria has 745.180, those defects of double outlet right ventricle which we have coded into 745.180 will not be counted in this defect.

 $3. Ventr\bar{i} cular\ Septal\ Defect:\ We\ are\ unable\ to\ distinguish\ inlet\ VSD\ from\ other\ types\ of\ VSD.$ 

- -Due to migration to Oracle data base, Texas can not access 2010 data at this time.
- -Our case definition includes livebirths, stillbirths, and terminations at any length of gestation and any birth weight.
- -Texas only reports confirmed and definite diagnoses for any defect reported. Possible/probable cases are not given.
- -Texas uses the CDC/BPA coding system, but does not use the new CDC/BPA codes.

Utah Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Amniotic bands	18 <b>0.9</b>	0 <b>0.0</b>	3 <b>0.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	22 <b>0.8</b>		
Anencephalus	56	1	11	2	2	73		
Aniridia	2.7 1	<b>3.9</b> 0	2.5 0	2.2 0	<b>5.8</b> 0	2.7 1		
A nouhthalmia/miaranhthalmia	<b>0.0</b> 9	0.0	<b>0.0</b> 3	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 13		
Anophthalmia/microphthalmia	0.4	1 3.9	0.7	<b>0.0</b>	0.0	0.5		
Anotia/microtia	59 <b>2.8</b>	0 <b>0.0</b>	17 <b>3.9</b>	1 1.1	0 <b>0.0</b>	77 <b>2.9</b>		
Aortic valve stenosis	97	0	20	7	1	125		
Atrial septal defect	<b>4.</b> 7 848	<b>0.0</b> 14	<b>4.6</b> 191	7.7 48	<b>2.9</b> 15	<b>4.6</b> 1121		
	<b>40.7</b> 121	<b>54.3</b> 2	<b>43.8</b> 25	<b>53.1</b> 4	<b>43.8</b> 2	<b>41.5</b> 154		
Atrioventricular septal defect (endocardial cushion defect)	5.8	<sup>2</sup> <b>7.8</b>	<b>5.</b> 7	4.4	5.8	<b>5.</b> 7		
Biliary atresia	16 <b>0.8</b>	2 7.8	2 <b>0.5</b>	0 <b>0.0</b>	0 <b>0.0</b>	20 <b>0.</b> 7		
Bladder exstrophy	6	0	0	1	0	7		
Choanal atresia	<b>0.3</b> 18	0.0	<b>0.0</b> 2	1.1 0	0.0	<b>0.3</b> 20		
	0.9	0.0	0.5	0.0	0.0	0.7		
Cleft lip with and without cleft palate	307 <b>14.</b> 7	4 15.5	46 <b>10.5</b>	5 <b>5.5</b>	4 11.7	370 <b>13.</b> 7		
Cleft palate without cleft lip	144 <b>6.9</b>	0 <b>0.0</b>	17 <b>3.9</b>	9 <b>10.0</b>	5 <b>14.6</b>	176 <b>6.5</b>		
Coarctation of aorta	218	4	36	5	2	266		
Common truncus	10.5 14	15.5 1	<b>8.3</b>	5.5 0	<b>5.8</b> 0	<b>9.8</b> 16		
	<b>0.</b> 7	3.9	0.2	0.0	0.0	0.6		
Congenital cataract	66 <b>3.2</b>	1 <b>3.9</b>	4 <b>0.9</b>	2 2.2	1 2.9	74 <b>2.</b> 7		
Congenital hip dislocation	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>		
Diaphragmatic hernia	35	0	5	1	3	44		
Down syndrome (Trisomy 21)	1.7 285	<b>0.0</b> 5	1.1 84	1.1 14	<b>8.8</b> 3	<b>1.6</b> 401		
	13.7	19.4	19.3	15.5	8.8	14.8		
Ebstein anomaly	27 <b>1.3</b>	0 <b>0.0</b>	1 <b>0.2</b>	1 1.1	1 2.9	31 <b>1.1</b>		
Encephalocele	17	0	6	0	0	24		
Epispadias	<b>0.8</b> 0	<b>0.0</b> 0	<b>1.4</b> 1	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.9</b> 2		
Esophageal atresia/tracheoesophageal	<b>0.0</b> 52	0.0	<b>0.2</b> 18	0.0	<b>0.0</b>	<b>0.1</b> 77		
fistula	2.5	0.0	4.1	5 <b>5.5</b>	2.9	2.9		
Gastroschisis	92 <b>4.4</b>	4 15.5	24 5.5	11 12.2	6 17.5	137 <b>5.1</b>		
Hirschsprung disease (congenital	39	0	3	7	0	49		
megacolon) Hydrocephalus without spina bifida	<b>1.9</b> 86	<b>0.0</b> 5	<b>0.</b> 7 14	7. 7 1	<b>0.0</b> 2	1.8 108		
	<b>4.1</b> 75	19.4	<b>3.2</b> 14	1.1	5.8	<b>4.0</b> 92		
Hypoplastic left heart syndrome	3.6	2 7.8	3.2	1 <b>1.1</b>	0 <b>0.0</b>	3.4		
Hypospadias*	829 77.3	14 <b>103.6</b>	41 <b>18.5</b>	20 <b>41.</b> 7	5 <b>28.</b> 7	916 <b>65.9</b>		
Microcephalus	123	3	27	2	3	158		
Obstructive genitourinary defect	<b>5.9</b> 78	11.6 0	<b>6.2</b> 14	<b>2.2</b> 5	<b>8.8</b> 0	<b>5.8</b> 99		
	<b>3.</b> 7	0.0	3.2	5.5	0.0	3.7		
Omphalocele	67 <b>3.2</b>	3 11.6	14 3.2	1 <b>1.1</b>	0 <b>0.0</b>	86 3.2		
Pulmonary valve atresia and stenosis	318	3	58	23	4	409		
	15.3	11.6	13.3	25.4	11.7	15.1		

Utah Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Pulmonary valve atresia	23	0	8	5	0	38	
Pyloric stenosis	1.1 319 15.3	0.0 1 3.9	1.8 84 19.3	5.5 6 6.6	0.0 4 11.7	1.4 416 15.4	
Rectal and large intestinal atresia/stenosis		2 7.8	17 3.9	5 <b>5.5</b>	2 5.8	102 3.8	
Reduction deformity, lower limbs	35 1.7	1 <b>3.9</b>	5 <b>1.1</b>	4 <b>4.4</b>	0 <b>0.0</b>	45 <b>1.</b> 7	
Reduction deformity, upper limbs	102 <b>4.9</b>	1 <b>3.9</b>	25 <b>5.</b> 7	4 <b>4.4</b>	1 2.9	135 <b>5.0</b>	
Renal agenesis/hypoplasia	68 <b>3.3</b>	1 <b>3.9</b>	13 <b>3.0</b>	6 <b>6.6</b>	0 <b>0.0</b>	89 <b>3.3</b>	
Spina bifida without anencephalus	84 <b>4.0</b>	1 <b>3.9</b>	17 <b>3.9</b>	1 <b>1.1</b>	2 <b>5.8</b>	105 <b>3.9</b>	
Tetralogy of Fallot	73 <b>3.5</b>	1 <b>3.9</b>	16 <b>3. 7</b>	6 <b>6.6</b>	2 <b>5.8</b>	99 <b>3.</b> 7	
Total anomalous pulmonary venous return (TAPVR)	1.1 1.1	0 <b>0.0</b>	9 <b>2.1</b>	2 2.2	2 <b>5.8</b>	36 1.3	
Transposition of great arteries - All	96 <b>4.6</b>	2 7.8	18 <b>4.1</b>	4 4.4	1 2.9	123 <b>4.6</b>	
dextro-Transposition of great arteries (d-TGA)	51 <b>2.4</b>	0 <b>0.0</b>	6 1.4	2 2.2	0 <b>0.0</b>	59 <b>2.2</b>	
Tricuspid valve atresia and stenosis	27 1.3	1 <b>3.9</b>	7 <b>1.6</b>	3 <b>3.3</b>	0 <b>0.0</b>	38 1.4	
Trisomy 13	37 1.8	2 7.8	16 <b>3. 7</b>	1 <b>1.1</b>	0 <b>0.0</b>	56 <b>2.1</b>	
Trisomy 18	75 <b>3.6</b>	5 19.4	15 <b>3.4</b>	1 <b>1.1</b>	1 2.9	99 <b>3.</b> 7	
Ventricular septal defect	495 <b>23.</b> 7	14 54.3	117 26.8	18 <b>19.9</b>	7 <b>20.4</b>	653 24.2	
<b>Total Live Births</b>	208442	2579	43611	9045	3423	270156	
<b>Total Male Live Births</b>	107296	1352	22131	4797	1741	138913	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

Utah Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)								
Defect	35	35+	Total	Notes				
Down syndrome (Trisomy 21)	227	174	401					
	9.3	67.1	14.8					
Trisomy 13	38	18	56					
	1.6	6.9	2.1					
Trisomy 18	57	42	99					
	2.3	16.2	3.7					
<b>Total Live Births</b>	244199	25947	270156					

<sup>\*\*</sup>Total includes unknown maternal age

<sup>-</sup>Patent ductus arteriosus, Congenital Hip Dislocation, and Fetus or newborn affected by maternal alcohol use are not collected in Utah.

Vermont Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes	
Anencephalus	4 1.3	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	4 1.3		
Anotia/microtia	4	0.0	0	0.0	0.0	5		
Aortic valve stenosis	1.3 12	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	1.6 12		
Aortic vaive stenosis	4.0	0.0	0.0	<b>0.0</b>	0.0	3.8		
Atrial septal defect	129 <b>43.0</b>	3 <b>80.0</b>	2 <b>52.5</b>	0 <b>0.0</b>	2 <b>540.5</b>	139 <b>43.9</b>		
Atrioventricular septal defect (endocardial	11	1	0	0	0	13		
cushion defect) Bladder exstrophy	<b>3.7</b> 1	<b>26.</b> 7	<b>0.0</b> 0	<b>0.0</b> 0	0.0	<b>4.1</b>		
	0.3	0.0	0.0	0.0	0.0	0.3		
Cleft lip with and without cleft palate	35 11.7	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	36 11.4		
Cleft palate without cleft lip	22	0	0	0	0	22		
Coarctation of aorta	<b>7.3</b> 23	0.0	<b>0.0</b> 0	<b>0.0</b> 0	0.0	<b>6.9</b> 23		
	7.7	0.0	0.0	0.0	0.0	7.3		
Common truncus	2 <b>0.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.6</b>		
Diaphragmatic hernia	11	0	0	0	0	11		
Down syndrome (Trisomy 21)	<b>3.7</b> 36	<b>0.0</b>	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.0</b> 0	<b>3.5</b> 39		
	<b>12.0</b>	<b>26.</b> 7 0	<b>26.2</b> 0	<b>0.0</b> 0	0.0	12.3		
Ebstein anomaly	0.3	0.0	0.0	<b>0.0</b>	0 <b>0.0</b>	1 <b>0.3</b>		
Encephalocele	2 <b>0.</b> 7	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.6</b>		
Epispadias	1	0	0	0	0	1		
Esophageal atresia/tracheoesophageal	<b>0.3</b> 10	0.0	<b>0.0</b> 0	<b>0.0</b> 0	0.0	<b>0.3</b> 10		
fistula	3.3	0.0	0.0	0.0	0.0	3.2		
Gastroschisis	5 1.7	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	8 <b>2.5</b>	1	
Hypoplastic left heart syndrome	9	0	0	0	0	9		
Hypospadias*	<b>3.0</b> 116	<b>0.0</b>	0.0	<b>0.0</b> 1	<b>0.0</b> 0	2.8 120		
	74.9	55.2	0.0	38.3	0.0	73.4		
Obstructive genitourinary defect	155 <b>51.7</b>	3 <b>80.0</b>	1 <b>26.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	160 <b>50.5</b>		
Omphalocele	1	1	0	0	0	2	1	
Patent ductus arteriosus	<b>0.3</b> 44	<b>26.7</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.6</b> 46	2	
	14.7	26.7	0.0	0.0	0.0	14.5		
Pulmonary valve atresia and stenosis	37 <b>12.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	38 <b>12.0</b>		
Pulmonary valve atresia	1 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.3</b>		
Rectal and large intestinal atresia/stenosis	11	0	0	0	0	11		
Renal agenesis/hypoplasia	<b>3.7</b> 15	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>3.5</b> 15		
	5.0	0.0	0.0	0.0	0.0	4.7		
Spina bifida without anencephalus	9 <b>3.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	9 <b>2.8</b>		
Tetralogy of Fallot	17	2	0	0	0	19		
Transposition of great arteries - All	<b>5.</b> 7 13	53.3 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>6.0</b> 13		
	4.3	0.0	0.0	0.0	0.0	4.1		
dextro-Transposition of great arteries (d-TGA)	8 2.7	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	8 <b>2.5</b>		
Tricuspid valve atresia and stenosis	2	0	0	0	0	2		
Trisomy 13	<b>0.7</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.6</b>		
	0.3	0.0	0.0	0.0	0.0	0.3		

Vermont Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity									
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacifi Islander Non-Hispanic	American c Indian or Alaska Native Non-Hispanic	Total**	Notes		
Trisomy 18	3	0	0	0	0	3			
	1.0	0.0	0.0	0.0	0.0	0.9			
Ventricular septal defect	186	3	3	2	0	196			
•	62.1	80.0	7 <b>8.</b> 7	<b>40.</b> 7	0.0	61.8			
<b>Total Live Births</b>	29970	375	381	492	37	31698			
<b>Total Male Live Births</b>	15487	181	185	261	21	16350			

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

# Vermont

# Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)								
Defect	Less than 35	35+	Total**	Notes				
Down syndrome (Trisomy 21)	18	21	39					
· · · · · · · · · · · · · · · · · · ·	6.8	40.2	12.3					
Trisomy 13	1	0	1					
•	0.4	0.0	0.3					
Trisomy 18	2	1	3					
·	0.8	1.9	0.9					
Total Live Births	26468	5230	31698					

<sup>\*\*</sup>Total includes unknown maternal age

#### Notes

- 1.Vermont uses ICD-9 codes but also reviews hospital records and repair procedures to differentiate between Gastroschisis and Omphalocele.
- 2.Included only if weight greater than or equal to 2500 grams.

- -Vermont birth data represents births to Vermont residents, regardless of which state the birth occurred in. Non-resident births occurring in Vermont are excluded.
- -Vermont predominately uses the ICD-9-CM coding system and does not include probable cases.
- -Vermont's program only collects data on live births.

Virginia Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Anencephalus	25	7	8	5	0	62	- 1000	
Aniridia	<b>0.8</b> 5	<b>0.6</b> 0	1.1 0	1.4 0	0.0	6		
Allingia	0.2	0.0	0.0	<b>0.0</b>	0.0	0.1		
Anophthalmia/microphthalmia	17	6	4	0	0	31		
Anotia/microtia	<b>0.6</b> 17	<b>0.5</b> 10	<b>0.6</b> 13	<b>0.0</b> 3	<b>0.0</b> 0	<b>0.6</b> 51		
7 mone merona	0.6	0.9	1.9	0.8	0.0	1.0		
Aortic valve stenosis	44 1.5	5 <b>0.4</b>	8 1.1	3 <b>0.8</b>	0 <b>0.0</b>	82 <b>1.5</b>		
Atrial septal defect	2408	1121	993	429	6	6125		
	79.5	97.8	142.4	116.7	77.6	115.7		
Atrioventricular septal defect (endocardial cushion defect)	99 <b>3.3</b>	57 <b>5.0</b>	14 <b>2.0</b>	10 <b>2.</b> 7	0 <b>0.0</b>	222 <b>4.2</b>		
Biliary atresia	17	4	2	2	0	29		
Dladdar avatranky	<b>0.6</b> 6	<b>0.3</b> 2	0.3	0.5	<b>0.0</b> 0	<b>0.5</b> 10		
Bladder exstrophy	0.2	0.2	0 <b>0.0</b>	1 <b>0.3</b>	<b>0.0</b>	0.2		
Choanal atresia	43	13	8	2	0	81		
Cleft lip with and without cleft palate	1.4 275	1.1 50	<b>1.1</b> 73	<b>0.5</b> 21	<b>0.0</b>	1.5 528		
Cleft lip with and without cleft parate	9.1	4.4	10.5	5.7	12.9	10.0		
Cleft palate without cleft lip	195	40	34	27	0	378		
Coarctation of aorta	<b>6.4</b> 149	3.5 40	<b>4.9</b> 30	7.3 13	<b>0.0</b> 0	7.1 287		
	4.9	3.5	4.3	3.5	0.0	5.4		
Common truncus	14 <b>0.5</b>	11 <b>1.0</b>	4 <b>0.6</b>	3 <b>0.8</b>	0 <b>0.0</b>	37 <b>0.</b> 7		
Congenital cataract	24	16	6	2	0	59		
	0.8	1.4	0.9	0.5	0.0	1.1		
Congenital hip dislocation	165 <b>5.4</b>	23 <b>2.0</b>	39 <b>5.6</b>	16 <b>4.4</b>	0 <b>0.0</b>	293 <b>5.5</b>		
Diaphragmatic hernia	53	37	23	2	0	136		
Down syndrome (Trisomy 21)	1.7 322	<b>3.2</b> 114	<b>3.3</b> 113	<b>0.5</b> 43	<b>0.0</b> 0	<b>2.6</b> 732		
Down syndrome (11130my 21)	10.6	9.9	16.2	11.7	0.0	13.8		
Ebstein anomaly	22	10	4	5 <b>1.4</b>	0 <b>0.0</b>	61		
Encephalocele	<b>0.7</b> 15	<b>0.9</b> 4	<b>0.6</b> 4	0	0.0	1.2 29		
	0.5	0.3	0.6	0.0	0.0	0.5		
Epispadias	31 <b>1.0</b>	14 1.2	5 <b>0.</b> 7	1 <b>0.</b> 3	0 <b>0.0</b>	59 <b>1.1</b>		
Esophageal atresia/tracheoesophageal	74	31	10	3	0	133		
fistula	2.4	2.7	1.4	0.8	0.0	2.5		
Fetus or newborn affected by maternal alcohol use	16 <b>0.5</b>	11 <b>1.0</b>	3 <b>0.4</b>	0 <b>0.0</b>	0 <b>0.0</b>	39 <b>0.</b> 7		
Gastroschisis	20	8	6	1	0	67		
Hirschsprung disease (congenital	<b>0.7</b> 62	<b>0.7</b> 31	<b>0.9</b> 7	<b>0.3</b> 4	<b>0.0</b> 0	1.3 130		
megacolon)	2.0	2.7	1.0	1.1	0.0	2.5		
Hydrocephalus without spina bifida	123	88	33	10	0	313		
Hypoplastic left heart syndrome	<b>4.1</b> 58	7.7 21	<b>4.</b> 7 14	<b>2.</b> 7	<b>0.0</b>	5.9 125		
	1.9	1.8	2.0	0.8	12.9	2.4		
Hypospadias*	875 <b>57.1</b>	261 44.7	91 <b>25.4</b>	73 <b>38.8</b>	0 <b>0.0</b>	1560 <b>58.0</b>		
Microcephalus	112	65	47	17	0.0	301		
•	3.7	<b>5.</b> 7	<b>6.</b> 7	4.6	0.0	5.7		
Obstructive genitourinary defect	631 <b>20.8</b>	180 <b>15.</b> 7	144 <b>20.</b> 7	86 <b>23.4</b>	0 <b>0.0</b>	1279 <b>24.2</b>		
Omphalocele	5	4	2	1	0	25		
Patent ductus arteriosus	<b>0.2</b> 1864	<b>0.3</b> 1073	<b>0.3</b> 781	<b>0.3</b> 307	<b>0.0</b> 5	<b>0.5</b> 5170		
i ateni ductus arteriosus	61.5	93.6	112.0	83.5	64.7	97.7		

Virginia Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes	
Pulmonary valve atresia and stenosis	256	147	90	52	1	669		
Pyloric stenosis	<b>8.5</b> 440	<b>12.8</b> 89	<b>12.9</b> 79	<b>14.1</b> 16	<b>12.9</b>	<b>12.6</b> 713		
•	14.5	7.8	11.3	4.4	12.9	13.5		
Rectal and large intestinal atresia/stenosis	119 <b>3.9</b>	22 1.9	25 <b>3.6</b>	5 <b>1.4</b>	0 <b>0.0</b>	217 <b>4.1</b>		
Reduction deformity, lower limbs	31 1.0	15 1.3	2 <b>0.3</b>	3 <b>0.8</b>	1 12.9	61 1.2		
Reduction deformity, upper limbs	75 <b>2.5</b>	22 1.9	12 1.7	5 1.4	1 12.9	129 <b>2.4</b>		
Renal agenesis/hypoplasia	75 <b>2.5</b>	28 <b>2.4</b>	16 2.3	3 <b>0.8</b>	2 25.9	159 <b>3.0</b>		
Spina bifida without anencephalus	109 <b>3.6</b>	40 <b>3.5</b>	41 <b>5.9</b>	4 1.1	0 <b>0.0</b>	231 4.4		
Tetralogy of Fallot	104 <b>3.4</b>	55 <b>4.8</b>	22 3.2	12 <b>3.3</b>	0 <b>0.0</b>	245 <b>4.6</b>		
Transposition of great arteries - All	140 <b>4.6</b>	50 4.4	25 <b>3.6</b>	12 3.3	0 <b>0.0</b>	284 <b>5.4</b>		
Tricuspid valve atresia and stenosis	21 <b>0.</b> 7	12 <b>1.0</b>	5 <b>0.</b> 7	5 1.4	0 <b>0.0</b>	53 <b>1.0</b>		
Trisomy 13	17 <b>0.6</b>	7 <b>0.6</b>	11 <b>1.6</b>	1 <b>0.3</b>	0 <b>0.0</b>	54 <b>1.0</b>		
Trisomy 18	43 1.4	17 1.5	7 1.0	7 <b>1.9</b>	0 <b>0.0</b>	89 <b>1.</b> 7		
Ventricular septal defect	1220 4 <b>0.3</b>	396 34.5	418 <b>60.0</b>	159 <b>43.3</b>	3 38.8	2709 51.2		
Total Live Births	302884	114667	69722	36761	773	529380		
<b>Total Male Live Births</b>	153291	58359	35765	18821	387	268969		

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

Virginia Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age						
Defect	Less than 35	35 and greater	Total**	Notes		
Down syndrome (Trisomy 21)	325 7.3	272 <b>31.4</b>	732 <b>13.8</b>			
Trisomy 13	29 <b>0.</b> 7	22 <b>2.5</b>	54 <b>1.0</b>			
Trisomy 18	39 <b>0.9</b>	36 4.2	89 1.7			
Total Live Births	442835	86545	529380			

<sup>\*\*</sup>Total includes unknown maternal age

# Washington Birth Defects Counts and Prevalence 2006-2009 (Prevalence per 10,000 Live Births)

Maternal Race/E	Maternal Race/Ethnicity						
Defect	Total**	Notes					
Anencephalus	15 <b>0.4</b>						
Cleft lip with and without cleft palat	te 406 11.4						
Cleft palate without cleft lip	314 <b>8.8</b>						
Down syndrome (Trisomy 21)	461 <b>13.0</b>						
Epispadias	24 <b>0.</b> 7						
Hypospadias*	945 <b>51.9</b>						
Reduction deformity, lower limbs	64 <b>1.8</b>						
Reduction deformity, upper limbs	93 <b>2.6</b>						
Spina bifida without anencephalus	102 <b>2.9</b>						
<b>Total Live Births</b>	355278						
<b>Total Male Live Births</b>	182015						

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births
\*\*Total includes unknown race

## Washington

## Trisomy Counts and Prevalence by Maternal Age 2006-2009 (Prevalence per 10,000 Live Births)

Maternal Age (years)						
Defect	Total**	Notes				
Down syndrome (Trisomy 21)	461					
, , , ,	13.0					
<b>Total Live Births</b>	355278					

<sup>\*\*</sup>Total includes unknown maternal age

## **General comments**

- -Washington could not report case data by race.
  -Washington's case totals include 5-7% duplicate cases, depending on condition.

West Virginia Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Anencephalus	26 2.7	0	1 <b>8.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	28	
Anophthalmia/microphthalmia	2.7 2 <b>0.2</b>	0.0 0 0.0	8.1 0 0.0	0.0 0 0.0	0.0 0 0.0	2.8 2 0.2	
Anotia/microtia	4	0.0	0.0	0.0	0.0	4	
	0.4	0.0	0.0	0.0	0.0	0.4	
Aortic valve stenosis	11 <b>1.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	14 <b>1.4</b>	
Atrial septal defect	717 7 <b>5.</b> 7	18 <b>49.2</b>	2 16.3	3 33.4	0 <b>0.0</b>	916 <b>90.4</b>	
Atrioventricular septal defect	18	0	0	0	0	20	
(endocardial cushion defect)	1.9	0.0	0.0	0.0	0.0	2.0	
Biliary atresia	3 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.3</b>	
Bladder exstrophy	1 <b>0.1</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.2</b>	
Choanal atresia	2	0.0	0.0	0.0	0.0	5	
	0.2	0.0	0.0	0.0	0.0	0.5	
Cleft lip with and without cleft palate	24 <b>2.5</b>	1 <b>2.</b> 7	0 <b>0.0</b>	1 11.1	0 <b>0.0</b>	27 <b>2.</b> 7	
Cleft palate without cleft lip	60 <b>6.3</b>	1 <b>2.</b> 7	0 <b>0.0</b>	1 11.1	0 <b>0.0</b>	65 <b>6.4</b>	
Coarctation of aorta	27	1	0	0	0	31	
Common truncus	2.9 52	2.7	<b>0.0</b> 0	<b>0.0</b> 0	0.0	<b>3.1</b> 54	
	5.5	5.5	0.0	0.0	0.0	5.3	
Congenital cataract	3 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.3</b>	
Congenital hip dislocation	8 <b>0.8</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	10 <b>1.0</b>	
Diaphragmatic hernia	12	1	0	0	0	14	
Down syndrome (Trisomy 21)	1.3 48	2.7	0.0	<b>0.0</b> 0	0.0	1.4 70	
Ebstein anomaly	<b>5.1</b> 8	<b>8.2</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	0.0	<b>6.9</b> 8	
	0.8	0.0	0.0	0.0	0.0	0.8	
Encephalocele	2 <b>0.2</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 <b>0.3</b>	
Epispadias	7	0	0	0	0	8	
Esophageal atresia/tracheoesophageal	<b>0.</b> 7	0.0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.8</b> 13	
fistula	1.0	0.0	0.0	0.0	0.0	1.3	
Fetus or newborn affected by maternal alcohol use	15 <b>1.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	18 <b>1.8</b>	
Hirschsprung disease (congenital	11	2	0	0	0	16	
megacolon) Hydrocephalus without spina bifida	1.2 31	<b>5.5</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>1.6</b> 35	
Hypoplastic left heart syndrome	3.3 12	<b>0.0</b>	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>3.5</b> 18	
	1.3	2.7	0.0	0.0	0.0	1.8	
Hypospadias*	152 <b>33.1</b>	4 22.5	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	189 <b>38.4</b>	
Microcephalus	19 <b>2.0</b>	1 2.7	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	29 <b>2.9</b>	
Obstructive genitourinary defect	44	1	1	0	0.0 0 0.0	48	
Patent ductus arteriosus	<b>4.6</b> 260	2.7 13	8.1 0	<b>0.0</b>	0	4.7 304	1
Pulmonary valve atresia and stenosis	<b>27.5</b> 34	<b>35.5</b> 0	<b>0.0</b> 0	11.1 0	0.0	<b>30.0</b> 51	
	3.6	0.0	0.0	0.0	0.0	5.0	
Pulmonary valve atresia	6 <b>0.6</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	8 <b>0.8</b>	
Pyloric stenosis	68	1	0	1	0	78	
	7.2	2.7	0.0	11.1	0.0	<i>7.7</i>	

West Virginia Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

#### Maternal Race/Ethnicity American Asian or Pacific Indian or White Black Islander Alaska Native Non-Hispanic Non-Hispanic Defect Non-Hispanic Total\*\* Hispanic Non-Hispanic Notes Rectal and large intestinal atresia/stenosis 23 30 2.7 8.1 0.0 0.0 2.4 3.0 Reduction deformity, lower limbs 0 0 0 8 0.7 0.0 0.0 0.0 0.0 0.8 Reduction deformity, upper limbs 10 11 0.0 0.0 0.0 **2.**7 1.1 1.1 Renal agenesis/hypoplasia 30 26 0 0 0 0 0.0 0.0 2.7 0.0 0.0 3.0 Spina bifida without anencephalus 32 32 3.4 0.0 0.0 0.0 0.0 3.2 Tetralogy of Fallot 30 46 0 0 0 0.0 2.7 0.0 0.0 4.5 3.2 Total anomalous pulmonary venous return 2 0 0 0 0 4 (TAPVR) 0.2 0.0 0.0 0.0 0.0 0.4 Transposition of great arteries - All 18 27 1.9 0.0 0.0 0.0 0.0 2.7 dextro-Transposition of great arteries 12 17 1.3 0.0 0.0 0.0 0.0 1.7 Tricuspid valve atresia and stenosis 12 **1.2** 0 0 0 0 **0.**7 0.0 0.0 0.0 0.0 Tricuspid valve atresia 12 0.0 0.0 1.2 **0.**7 0.0 0.0 Trisomy 13 6 0.3 0.0 0.0 0.0 0.0 0.6 Trisomy 18 0 0 11 2.7 1.0 0.0 0.0 0.0 1.1 Ventricular septal defect 198 240 10.9 0.0 0.0 20.9 11.1 23.7 **Total Live Births** 94656 1227 899 119 101298 3660 45879 1781 600 458 55 49267 **Total Male Live Births**

\*\*Total includes unknown race

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births

West Virginia

## Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)						
Defect	Less than 35	35+	Total**	Notes		
Down syndrome (Trisomy 21)	32	14	70			
Trisomy 13	3.5 2	<b>16.6</b> 1	<b>6.9</b> 6			
	0.2	1.2	0.6			
Trisomy 18	6 <b>0.</b> 7	3 <b>3.5</b>	11 <b>1.1</b>			
<b>Total Live Births</b>	92251	8457	101298			

<sup>\*\*</sup>Total includes unknown maternal age

## Notes

1.Includes only births greater than or equal to 2500 grams or greater than or equal to 36 weeks gestation.

## **General comments**

- -Birth defects defined by ICD-9 coding.
  -Probable cases are included.
- -Stillbirths and terminations per birth defect are not collected.

Wisconsin Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Anencephalus	32	4	8	5	0	49	Notes
	1.3	1.1	2.4	3.5	0.0	1.5	
Aniridia	3 <b>0.1</b>	3 <b>0.9</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	6 <b>0.2</b>	
Anophthalmia/microphthalmia	15 <b>0.6</b>	4 1.1	1 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	20 <b>0.6</b>	
Anotia/microtia	18 <b>0. 7</b>	2 <b>0.6</b>	13 <b>3.9</b>	0 <b>0.0</b>	0 <b>0.0</b>	33 <b>1.0</b>	
Aortic valve stenosis	19 <b>0.8</b>	0.0 1 0.3	1 0.3	0.0 0 <b>0.0</b>	1 1.8	22 <b>0.</b> 7	
Atrial septal defect	1010 <b>40.6</b>	119 <b>34.1</b>	132 39.3	37 <b>26.1</b>	42 77. <b>0</b>	1340 39.8	
Atrioventricular septal defect	48	7	3	1	0	59	1
(endocardial cushion defect) Biliary atresia	1.9 3	<b>2.0</b> 0	<b>0.9</b> 0	<b>0.</b> 7 0	0.0	<b>1.8</b> 3	
	0.1	0.0	0.0	0.0	0.0	0.1	
Bladder exstrophy	8 <b>0.3</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	8 <b>0.2</b>	
Choanal atresia	32	1	5	1 <b>0.</b> 7	0 <b>0.0</b>	39	
Cleft lip with and without cleft palate	1.3 239 <b>9.6</b>	0.3 27 7.7	1.5 31 9.2	0.7 11 7.8	8 14.7	1.2 316 9.4	
Cleft palate without cleft lip	158	16	13	7	2	197	
Coarctation of aorta	<b>6.4</b> 41	<b>4.6</b> 8	3.9 7	<b>4.9</b> 0	3.7 1	5.8 57	
Common truncus	1.6 14 0.6	2.3 1 0.3	2.1 2 0.6	0.0 0 0.0	1.8 0 0.0	1.7 17 0.5	
Congenital cataract	19	4	3	0	0	27	
Congenital hip dislocation	<b>0.8</b> 164 <b>6.6</b>	1.1 6 1.7	0.9 23 6.8	0.0 4 2.8	0.0 0 0.0	<b>0.8</b> 197 <b>5.8</b>	
Diaphragmatic hernia	42 1.7	6 1.7	9 2.7	1 <b>0.</b> 7	1.8	59 1.8	
Down syndrome (Trisomy 21)	307 12.3	26 7.4	65 19.3	27 <b>19.1</b>	5 9.2	430 12.8	
Ebstein anomaly	4 0.2	0 <b>0.0</b>	2 0.6	19.1 1 0.7	1.8	8 0.2	
Encephalocele	9 <b>0.4</b>	1 0.3	0.0 0.0	1 <b>0.</b> 7	0 <b>0.0</b>	11 <b>0.3</b>	
Epispadias	19	5	2	1	0	27	
Esophageal atresia/tracheoesophageal	<b>0.8</b> 48	5	0.6	0.7 1 0.7	0.0	<b>0.8</b> 58	
fistula  Fetus or newborn affected by maternal	1.9 22	1.4	2	0	0.0 3	1.7 37	
alcohol use Hirschsprung disease (congenital	<b>0.9</b> 16	<b>2.9</b> 3	<b>0.6</b> 2	<b>0.0</b> 2	<b>5.5</b> 0	1.1 23	
megacolon) Hydrocephalus without spina bifida	<b>0.6</b> 88	<b>0.9</b> 23	0.6	1.4 2	0.0	<b>0.</b> 7 126	
	3.5	6.6	13 <b>3.9</b>	1.4	0 <b>0.0</b>	3.7	
Hypoplastic left heart syndrome	44 <b>1.8</b>	11 <b>3.1</b>	4 1.2	0 <b>0.0</b>	1 1.8	60 <b>1.8</b>	
Hypospadias*	959 <b>75.1</b>	129 <b>73.3</b>	57 <b>33.2</b>	14 <b>19.6</b>	11 <b>39.6</b>	1171 <b>67.9</b>	
Microcephalus	42 1.7	6 1.7	6 1.8	2 1.4	0 <b>0.0</b>	56 1.7	
Obstructive genitourinary defect	488 19.6	37 10.6	40 11.9	28 19.8	14 25.7	607 18.0	
Patent ductus arteriosus	701 28.2	115 32.9	110 32.7	31 21.9	27 49.5	984 <b>29.2</b>	
Pulmonary valve atresia and stenosis	63 2.5	20 5.7	11 3.3	4 2.8	4 7.3	102 3.0	
Pulmonary valve atresia	6 <b>0.3</b>	0 <b>0.0</b>	2 <b>0.</b> 7	1 <b>0.9</b>	0 <b>0.0</b>	9 <b>0.3</b>	

Wisconsin Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Non- Hispanic White	Non- Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaska Native	Total**	Notes
Pyloric stenosis	5	0	0	0	0	5	
	0.2	0.0	0.0	0.0	0.0	0.1	
Rectal and large intestinal atresia/stenosis		6	11	3	1	102	
D 1 4' 1 C '4 1 1' 1	3.3	1.7	3.3	2.1	1.8	3.0	
Reduction deformity, lower limbs	33 1.3	4	4 1.2	2 1.4	0 <b>0.0</b>	43 1.3	
Dadastian dafamaita anno a limba	62	1.1		3	2	85	
Reduction deformity, upper limbs	2.5	10 <b>2.9</b>	8 <b>2.4</b>	2.1	3.7	2.5	
Renal agenesis/hypoplasia	97	7	6	3	1	114	
Renar agenesis/hypopiasia	3.9	2.0	1.8	2.1	1.8	3.4	
Spina bifida without anencephalus	74	9	10	2	1	96	
~ F	3.0	2.6	3.0	1.4	1.8	2.8	
Tetralogy of Fallot	60	16	11	3	1	91	
	2.4	4.6	3.3	2.1	1.8	2.7	
Total anomalous pulmonary venous return		1	1	0	0	7	
(TAPVR)	0.2	0.3	0.3	0.0	0.0	0.2	
Transposition of great arteries - All	50	5	11	0	3	69	
	2.0	1.4	3.3	0.0	5.5	2.0	
dextro-Transposition of great arteries	27	2	4	0	1	34	
(d-TGA)	1.3	0.7	1.5	0.0	2.3	1.2	2
Tricuspid valve atresia and stenosis	17 <b>0.</b> 7	3 <b>0.9</b>	2	2 1.4	0	24 <b>0.</b> 7	2
Triidlti-			0.6		0.0		
Tricuspid valve atresia	1 <b>0.0</b>	0 <b>0.0</b>	1 <b>0.4</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 <b>0.1</b>	
Trisomy 13	20	3	3	1	0.0	27	
Trisoniy 15	0.8	0.9	0.9	0.7	0.0	0.8	
Trisomy 18	50	7	6	2	0.0	66	
	2.0	2.0	1.8	1.4	0.0	2.0	
Ventricular septal defect	619	61	122	33	20	855	3
1	24.9	17.5	36.3	23.3	36.6	25.4	
<b>Total Live Births</b>	248656	34946	33608	14170	5458	337011	
<b>Total Male Live Births</b>	127709	17602	17172	7157	2778	172507	

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births \*\*Total includes unknown race

Wisconsin Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Age						
Defect	Less than 35	35 and greater	Total**	Notes		
Down syndrome (Trisomy 21)	231 7.9	199 <b>45.9</b>	430 <b>12.8</b>			
Trisomy 13	18 <b>0.6</b>	9 <b>2.</b> 1	27 <b>0.8</b>			
Trisomy 18	40 1.4	26 <b>6.0</b>	66 <b>2.0</b>			
Total Live Births	293689	43322	337011			

<sup>\*\*</sup>Total includes unknown maternal age

## Notes

- 1.Cannot include Inlet VSD, common atrioventricular (AV) canal type VSD.
  2.Cases with tricuspid stenosis or hypoplasia are included.
  3.Including probable cases, cannot exclude; Hospital practice in coding is not known.

# Department of Defense Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

		Maternal R	ace/Ethnicity				
<u>D</u> efect	White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian or Pacific Islander Non-Hispanic	American Indian or Alaska Native Non-Hispanic	Total**	Notes
Anencephalus	22	7	5	3	0	38	1
Aniridia	<b>0.6</b> 7	<b>0.9</b> 1	<b>0.8</b> 0	1.2 0	<b>0.0</b> 0	<b>0.</b> 7	
	0.2	0.1	0.0	0.0	0.0	0.1	
Anophthalmia/microphthalmia	59 <b>1.6</b>	19 <b>2.3</b>	13 <b>2.0</b>	5 <b>1.9</b>	3 <b>2.9</b>	100 <b>1.8</b>	
Anotia/microtia	69	12	12	5	4	103	
	1.8	1.5	1.9	1.9	3.8	1.8	
Aortic valve stenosis	144 <b>3.8</b>	20 2.5	18 <b>2.8</b>	6 <b>2.3</b>	5 <b>4.8</b>	194 <b>3.4</b>	
Atrial septal defect	3189	755	541	185	77	4843	2
	84.7	93.0	85.1	71.8	73.8	85.0	2
Atrioventricular septal defect (endocardial cushion defect)	223 <b>5.9</b>	58 <b>7.1</b>	40 <b>6.3</b>	10 <b>3.9</b>	5 <b>4.8</b>	342 <b>6.0</b>	3
Biliary atresia	39	9	9	2	1	60	
DI II	1.0	1.1	1.4	0.8	1.0	1.1	
Bladder exstrophy	16 <b>0.4</b>	2 <b>0.2</b>	2 <b>0.3</b>	1 <b>0.4</b>	0 <b>0.0</b>	21 <b>0.4</b>	
Choanal atresia	107	17	13	3	2	143	
Cl-8 lin mith and mith and alask malata	2.8	2.1	2.0	1.2 30	1.9 8	<b>2.5</b> 647	
Cleft lip with and without cleft palate	485 <b>12.9</b>	50 <b>6.2</b>	60 <b>9.4</b>	30 <b>11.6</b>	8 7.7	04 / 11.4	
Cleft palate without cleft lip	460	62	63	23	7	629	
Coarctation of aorta	12.2 343	7.6 68	<b>9.9</b> 47	<b>8.9</b> 15	<b>6.7</b> 10	<b>11.0</b> 491	
Coarctation of aorta	9.1	8. <i>4</i>	7.4	5.8	9.6	8.6	
Common truncus	87	15	13	5	3	123	
Congenital cataract	2.3 110	1.8 25	<b>2.0</b> 30	1.9 8	<b>2.9</b> 1	2.2 176	
Congenital catalact	2.9	3.1	4.7	3.1	1.0	3.1	
Congenital hip dislocation	800 <b>21.3</b>	84 <b>10.3</b>	116 <b>18.2</b>	41 <b>15.9</b>	26 <b>24.9</b>	1088 <b>19.1</b>	
Diaphragmatic hernia	157	26	24	9	2	219	
	4.2	3.2	3.8	3.5	1.9	3.8	
Down syndrome (Trisomy 21)	550 <b>14.6</b>	105 <b>12.9</b>	90 <b>14.2</b>	35 <b>13.6</b>	9 <b>8.6</b>	804 <b>14.1</b>	1
Ebstein anomaly	39	8	7	3	3	63	
	1.0	1.0	1.1	1.2	2.9	1.1	
Encephalocele	38 <b>1.0</b>	12 <b>1.5</b>	12 <b>1.9</b>	3 1.2	3 <b>2.9</b>	69 <b>1.2</b>	
Epispadias	57	16	8	3	1	85	
Ehlhhh	1.5 112	2.0	1.3	<b>1.2</b> 5	<b>1.0</b>	1.5	
Esophageal atresia/tracheoesophageal fistula	3.0	20 2.5	10 <b>1.6</b>	i.9	1.0	151 <b>2.6</b>	
Fetus or newborn affected by maternal	26_	4	1	0	0	31	
alcohol use Hirschsprung disease (congenital	<b>0.7</b> 141	<b>0.5</b> 44	<b>0.2</b> 30	<b>0.0</b> 14	<b>0.0</b> 7	<b>0.5</b> 245	
megacolon)	3.7	5.4	<b>4.</b> 7	5.4	6.7	4.3	
Hydrocephalus without spina bifida	361	89	46	20	9	534	
Hypoplastic left heart syndrome	<b>9.6</b> 158	<b>11.0</b> 40	7.2 23	<b>7.8</b> 9	<b>8.6</b> 7	<b>9.4</b> 243	
Trypoplastic left heart syndrome	4.2	4.9	3.6	3.5	6.7	4.3	
Hypospadias*	2060	376	235	119	49	2911	
Microcephalus	106.2 386	<b>91.2</b> 97	<b>72.4</b> 53	<b>88.9</b> 24	<b>92.0</b> 7	<b>99.4</b> 579	
	10.3	11.9	8.3	9.3	6.7	10.2	
Obstructive genitourinary defect	1736 <b>46.1</b>	264	308 <b>48.4</b>	115 <b>44.6</b>	49 <b>46.9</b>	2512 <b>44.1</b>	
Pulmonary valve atresia and stenosis	<b>46.1</b> 684	<b>32.5</b> 207	<b>48.4</b> 118	<b>44.6</b> 37	<b>46.9</b> 19	1082	
	18.2	25.5	18.6	14.4	18.2	19.0	
Pulmonary valve atresia	92 <b>2.4</b>	24 3.0	16 2.5	9 <b>3.5</b>	2 1.9	146 <b>2.6</b>	
Pyloric stenosis	1068	92	157	28	33	1405	
-	28.4	11.3	24.7	10.9	31.6	24.7	

## Department of Defense Birth Defects Counts and Prevalence 2006-2010 (Prevalence per 10,000 Live Births)

#### Maternal Race/Ethnicity American Asian or Pacific Indian or White Black Islander Alaska Native Defect Non-Hispanic Non-Hispanic Non-Hispanic Total\*\* Hispanic Non-Hispanic Notes Rectal and large intestinal atresia/stenosis 238 35 25 337 3.9 10.5 5.9 6.3 4.3 4.8 Reduction deformity, lower limbs 101 26 11 4 149 2.7 3.2 **1.**7 1.6 3.8 2.6 130 Reduction deformity, upper limbs 21 25 188 3.8 2.6 3.9 **2.**7 3.5 3.3 307 Renal agenesis/hypoplasia 215 26 41 13 6 5.7 **5.** 7 3.2 5.0 5.4 6.4 Spina bifida without anencephalus 196 28 28 10 10 279 9.6 3.4 4.4 3.9 4.9 5.2 Tetralogy of Fallot 227 25 **9.**7 48 40 352 5.9 **6.**7 6.0 6.3 6.2 Total anomalous pulmonary venous return 52 15 14 89 4 0 (TAPVR) 0.0 1.4 1.8 2.2 1.6 1.6 Transposition of great arteries - All 33 35 308 216 15 5.5 **5.** 7 4.1 5.8 3.8 5.4 dextro-Transposition of great arteries 145 20 20 12 203 3.9 2.5 3.1 4.7 1.9 3.6 Tricuspid valve atresia and stenosis 17 86 56 4 5 1 1.9 2.1 1.0 1.5 1.5 0.6 Trisomy 13 40 19 68 1.1 2.3 1.1 0.4 0.0 1.2 Trisomy 18 70 14 99 1.9 1.1 2.2 1.9 0.0 1.7 Ventricular septal defect 2814 481 452 158 73 4051 4 69.9 74.8 59.2 71.1 61.3 71.1 **Total Live Births** 376395 81201 63572 25768 10440 569832 **Total Male Live Births** 194057 41247 32457 13382 5324 292921

\*\*Total includes unknown race

<sup>\*</sup>Hypospadias: prevalence per 10,000 male live births

## **Department of Defense**

## Trisomy Counts and Prevalence by Maternal Age 2006-2010 (Prevalence per 10,000 Live Births)

Maternal Age (years)						
Defect	Less than 35	35+	Total**	Notes		
Down syndrome (Trisomy 21)	508 <b>10.2</b>	272 <b>52.9</b>	804 <b>14.1</b>	1		
Trisomy 13	56 <b>1.1</b>	10 <b>1.9</b>	68 1.2	1		
Trisomy 18	60 1.2	34 <b>6.6</b>	99 <b>1.</b> 7	Ī		
<b>Total Live Births</b>	497466	51421	569832			

<sup>\*\*</sup>Total includes unknown maternal age

## Notes

- 1.DoD Registry only captures livebirths
  2.DoD Registry relies on ICD-9-CM codes and cannot differentiate PFO
- 3.DoD Registry relies on ICD-9-CM codes and cannot distinguish 745.487
- 4.All ICD-9-CM coded cases that meet DoD Registry case criteria are included. DoD Registry relies on ICD-9-CM codes and cannot distinguish 745.487

## General comments

- -Criteria for a case: One diagnosis from institutional records, or 2 diagnoses from professional encounter records -Infants that appear as multiples of same gender are excluded from analysis
- -Race/Ethnicity for the DoD Birth and Infant Health Registry is based on the military parent through whom the infant receives military health care benefits. This may be the infants' mother or father.

# STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Updated August 2013

Prepared by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Acknowledgement: State birth defects program directors provided the information for the directory. Their names can be found under the "contact" section of each state profile.

## Alabama

Program status: No surveillance program

**Contacts** 

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Rachel Montgomery, RN, BSN Alabama Newborn Screening Program 201 Monroe Street Montgomery, AL 36104

## Alaska

Alaska Birth Defects Registry (ABDR)

Purpose: Surveillance, Research

**Partner**: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early

Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1996

Earliest year of available data: 1996

*Organizational location*: Department of Health and Social Services, Division of Public Health, Section of Women's, Children's and Family

Health, Maternal Child Health Epidemiology *Population covered annually*: 11,000

Statewide: Yes

Current legislation or rule: 7 AAC 27.012

Legislation year enacted: 1996

Case Definition

*Outcomes covered*: ICD-9 Codes 237.7, 243, 255.2, 270, 271, 277, 279, 282, 284.0, 331, 334, 335, 343, 359, 362.74, 389, 740-760, 760.71

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: Birth to sixth birthday

Residence: In and out of state births to Alaska residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based, Passive case ascertainment with case verification of selected conditions including FAS and NTDs

Vital Records: Birth certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Genetics clinics, Specialty clinics (heart, cleft lip/palate, neurodevelopmental), MIMR (FIMR), Public health nursing Delivery hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-9 code.

*Pediatric & tertiary care hospitals*: Disease index or discharge index, Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-9 code.

Third party payers: Medicaid databases, Indian health services

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD-9 code of 760.71 and other birth defects as selected for review by the ABDR Program Manager.

Coding: ICD-9-CM

## Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic information

#### Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access

Data Analysis

Data analysis software: Epi-Info, SAS, Access

**Quality assurance**: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness, Record linkage and de-duplication

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Grant proposals, Education/public awareness, Prevention projects, Monitoring outbreaks and cluster

investigations

**System Integration** 

System links: Link case finding data to final birth file

**Funding** 

Funding Source: 80% general state funds, 20% MCH funds

**Other** 

Web site: www.epi.alaska.gov/mchepi/ABDR Surveillance reports on file: see website

Contacts

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E-mail: hssbirthdefreg@alaska.gov

## Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

Purpose: Surveillance, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy

Groups, Legislators

Program status: Currently collecting data

Start year: 1986

Earliest year of available data: 1986

Organizational location: Department of Health (Bureau of Public Health

Statistics/Office of Health Registries)

Population covered annually: 87,053 live births and 443 spontaneous

fetal losses in AZ to AZ residents, 2010

Statewide: Yes

Current legislation or rule: Statutewww.azleg.state.az.us/ars/36/00133.htm

Rule- www.azsos.gov/public\_services/Title\_09/9-04.htm; Effective 1991

Legislation year enacted: 1988

#### Case Definition

Outcomes covered: Major birth defects and genetic diseases, as defined by the BPA/MACDP codes. Covered conditions vary by year of birth. Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, Stillbirths with a fetal death certificate can be of any

gestational age or weight), Terminations are not included in the electronic

database

Age: Up to one year after delivery. If the nature of a defect diagnosed in the first year of life is more precisely diagnosed later in the child's life, and this information is contained in the chart at the time of our review (which occurs 2-3 years after the child's birth or fetal death), then the more precise diagnosis is used.

**Residence**: Cases are born in Arizona and have an Arizona abstract indicating mother's residence in AZ

## Surveillance Methods

Case ascertainment: Active case ascertainment, Population based, 1986-2004: 44 categories; 2005-2009: 31 categories; 2010: 32 categories of

defects; 2011:34 categories of defects.

Vital Records: Birth certificates, Fetal death certificates

Other state based registries: Programs for children with special needs,

Newborn hearing screening program

Delivery hospitals: Disease index or discharge index, Discharge

summaries, Mother's chart for stillborn

Pediatric & tertiary care hospitals: Disease index or discharge index,

Discharge summaries, Mother's chart for stillborn *Third party payers*: Indian Health Services

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: CDC coding system based on BPA

## Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, length, gestation, etc.), Tests and procedures used to make birth defect diagnosis

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## **Data Collection Methods and Storage**

Data Collection: Hard copy abstract/report filled out by ABDMP staff

Database storage/management: Access, Oracle

## Data Analysis

Data analysis software: SAS, Access

*Quality assurance*: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

## **System Integration**

System links: Link to other state registries/databases, Link case finding data to final birth file

## **Funding**

Funding Source: 15% general state funds, 14% MCH funds, and 71% CDC Cooperative grant funds

## **Other**

Web site: http://www.azdhs.gov/phs/phstats/bdr/index.htm

Surveillance reports on file: Same as Above

## **Contacts**

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## Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

Purpose: Surveillance, Research, Referral to Prevention/InterventionPartner: Local Health Departments, Universities, Hospitals, Advocacy

Groups, Legislators

Program status: Currently collecting data

Start year: 1980

Earliest year of available data: 1980

Organizational location: University, Arkansas Children's Hospital

Population covered annually: 41,000

Statewide: Yes

Current legislation or rule: Senate Bill Act 214

Legislation year enacted: 1985

Case Definition

Outcomes covered: major structural birth defects

*Pregnancy outcome*: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational

ages), Elective Terminations (All gestational ages)

Age: two years after delivery

Residence: in and out of state births to state residents

Surveillance Methods

Case ascertainment: Active case ascertainment, Population based

Vital Records: Birth certificates

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs,

ICU/NICU logs or charts

**Pediatric & tertiary care hospitals**: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient

clinics

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.),

Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes 740-759, All stillborn infants

Conditions warranting chart review beyond the newborn period: Any

infant with a codeable defect

Coding: locally modified BPA/CDC and NBDPS coding system

Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures,

Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity,

Prenatal diagnostic information, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility

(laptop, web-based, etc.)

Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access, STATA

**Quality assurance**: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review,

Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Prevention projects

**System Integration** 

System links: Link case finding data to final birth file

**Funding** 

Funding Source: 100% general state funds

**Other** 

Web site: http://arbirthdefectsresearch.uams.edu/

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## California

California Birth Defects Monitoring Program (CBDMP)

Purpose: Surveillance, Research

Partner: Local Health Departments, Universities, Hospitals,

Environmental Agencies/Organizations **Program status**: Currently collecting data

Start year: 1983

Earliest year of available data: 1983

*Organizational location*: Department of Health (California Department of Public Health: Maternal, Child, Adolescent Health Division, Center for

Family Health)

Population covered annually: 70,000

Statewide: No, The Program currently monitors a sampling of California births that are demographically similar to the state as a whole and whose birth defects rates and trends have been reflective of those throughout California. Furthermore, the Program has statutory authority to conduct active surveillance anywhere in the state when warranted by environmental incidents or concerns.

Current legislation or rule: Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855, effective 1982, recodified 1996. Legislation year enacted: 1982

Case Definition

Outcomes covered: Serious structural birth defects, primarily

encompassed within ICD codes 740-759 *Pregnancy outcome*: Live Births (All gestational ages and birth weights),

Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), Elective Terminations (less than 20 week gestation, 20 weeks gestation and greater)

Age: one year

**Residence**: In-state births to residents of 1 of 8 counties; does not include births in military hospitals.

## Surveillance Methods

Case ascertainment: Active case ascertainment, Population based Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases, Apgar 0-0 Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), GU condition (e.g., recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codeable defect

Coding: CDC BPA coding system but modified for use in California

## Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity,

Illnesses/conditions, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility

(laptop, web-based, etc.)

Database storage/management: SQL server

## Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Validity checks are done on all abstracts. Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Capture-recapture analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Grant proposals, Education/public awareness

## **System Integration**

System links: Link case finding data to final birth file, Hospital discharge. CBDMP links case finding data to final vital statistics birth and fetal death files

## Funding

Funding Source: 100% special fund

## <u>Other</u>

Web site: www.cdph.ca.gov/programs/CBDMP

Comments: Please send inquiries to mchinet@cdph.ca.gov.

## Contacts

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## Colorado

Colorado Responds To Children With Special Needs: Colorado (CRCSN)

Purpose: Surveillance, Referral to Services, Referral to

Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Community

Nursing Services, Environmental Agencies/Organizations, Early

Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1988

Earliest year of available data: 1989

Organizational location: Department of Health

(Epidemiology/Environment)

Population covered annually: 65,188(2012)

Statewide: Yes

Current legislation or rule: Colorado Revised Statutes (CRS) 25-1.5-101

- 25-1.5-105

Legislation year enacted: 1985

## Case Definition

*Outcomes covered*: Structural birth defects, fetal alcohol syndrome, selected genetic and metabolic disorders; muscular dystrophy; selected developmental disabilities; very low birth weight (less than 1500 grams); others with medical risk factors for developmental delay

*Pregnancy outcome*: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater, less than 20 week limited to selected post-mortem pathology sites)

*Age*: up to the 3rd birthday (up to the 10th birthday for fetal alcohol syndrome)

Residence: events occurring in-state or out-of-state to Colorado residents

## Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment

Vital Records: Birth certificates, Death certificates, Fetal death certificates

Other state based registries: Newborn hearing screening program,

Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index,

Postmortem/pathology logs, Specialty outpatient clinics, selected postmortem pathology sites

**Pediatric & tertiary care hospitals**: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics, selected postmortem pathology sites

Third party payers: Medicaid databases

Other specialty facilities: Cytogenetic laboratories, Genetic

counseling/clinical genetics facilities

Other sources: Physician reports, selected sites for fetal alcohol

syndrome and muscular dystrophy

## Case Ascertainment

Conditions warranting chart review in newborn period: selected chart reviews for prenatal to age 3: for statistical trends monitoring (20 conditions - categories); selected death and fetal deaths; fetal alcohol syndrome (to age 10); active case ascertainment data sources (postmortem pathology and specialty clinics); quality control (selected procedures); and others as needed.

**Coding**: ICD-9-CM, extended code utilized to describe syndromes, further detail of a condition, and to specify status

## **Data Collected**

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic information

**Mother**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications,

Maternal risk factors

Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

## Data Collection Methods and Storage

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), 99% of data are collected in electronic format Database storage/management: Access, Conversion to SQL Server

#### Data Analysis

Data analysis software: SAS, Access, ArcView (GIS software), Maptitude, SaTScan

Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness, ongoing quality control procedures for problematic conditions and situations; records linkage and de-duplication. Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies. Needs

Prevention projects, environmental studies

## **System Integration**

System links: Link to other state registries/databases, Ongoing match to vital records files (birth, death, fetal death)

assessment, Referral, Grant proposals, Education/public awareness,

## **Funding**

Funding Source: 26% General state Funds, 31% Service fees, 43% CDC grant

## <u>Other</u>

Web site: http://www.cdphe.state.co.us

## Contacts

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## Connecticut

Connecticut Birth Defects Registry (CTBDR)

*Purpose*: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, reporting for MCH Block Grant

**Partner**: Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, CT Council on

Genomics

Program status: Currently collecting data

Start year: 2002

Earliest year of available data: 2000

Organizational location: Department of Health (Maternal and Child

Health)

Population covered annually: 43,000

Statewide: Yes

Current legislation or rule: Sec. 19a-56a. (Formerly Sec. 10a-132b), Birth defects surveillance program; Sec. 19a-54. (Formerly Sec. 19-21a), Registration of physically handicapped children; Sec. 19a-53. (Formerly Sec. 19-21), Reports of physical defects of children. Legislation year enacted: Sec. 10a-132b: 1991; Sec. 19-21a: 1949 Sec.

19-21: 1949.

#### Case Definition

Outcomes covered: All major structural birth defects; biochemical, genetic and hearing impairment through linkage with Newborn Screening System; any condition that places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.) ICD-9 codes 740 thru 759.9 and 760.71

**Pregnancy outcome**: Live Births (All gestational ages and birth weights, Other gestational age and/or birth weight criterion, PDA  $\geq$  to 2500 grams birth weight)

Age: Up to one year after delivery for birth defects **Residence**: In state births to state residents

## Surveillance Methods

*Case ascertainment*: Passive case ascertainment, Population based *Vital Records*: Birth certificates, Death certificates, Matched birth/death file, inpatient hospitalizations and emergency room visits

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Reports from health care professionals in newborn nurseries and NICUs.

**Pediatric & tertiary care hospitals**: Disease index or discharge index, Discharge summaries, Reports from health care professionals in pediatric inpatient and outpatient services planned for future.

Midwifery facilities: Midwifery facilities

*Other sources*: Physician reports, Mandatory reporting by health care providers and facilities; CSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

#### Case Ascertainment

Coding: ICD-9-CM, test written in 'other' field categories

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

## Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access, Oracle

## Data Analysis

Data analysis software: SAS, Access, STATA, Arc GIS

Quality assurance: Validity checks, Comparison/verification between

multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, Provider education

## **System Integration**

System links: Link case finding data to final birth file

## Funding

Funding Source: 100% MCH funds

## **Other**

Web site: http://www.ct.gov/dph/birthdefectsregistry

## Contacts

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## **Delaware**

Delaware Birth Defects Surveillance Project

**Purpose**: Surveillance, Referral to Prevention/Intervention **Partner**: Hospitals, Early Childhood Prevention Programs

Program status: Currently collecting data

Start year: 2007

Earliest year of available data: 2007, 2008, 2009

Organizational location: Department of Health and Social Services,

Division of Public Health, Family Health Services

Population covered annually: 12,000

Statewide: Yes

Current legislation or rule: House Bill No. 197, an act to amend Title 16

of the Delaware Code relating to Birth Defects

Legislation year enacted: 1997

## Case Definition

*Outcomes covered*: Birth Defects Registry - Selected birth defects for passive surveillance, developmental disabilities if due to a birth defect, selected metabolic defects, genetic diseases, infant mortality, congenital infections. Autism

**Pregnancy outcome**: Live Births (Other gestational age and/or birth weight criterion, any gestation for live birth, greater than 20 weeks for fetal death), Fetal deaths - (stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: birth to 5 years

Residence: in-state and out-of-state birth to state resident, and in-state

birth to state non-resident.

## Surveillance Methods

Case ascertainment: Combination of active and passive case

ascertainment, Population based

Vital Records: Birth certificates, Death certificates, hospital discharge

records/data

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance, Cancer registry, AIDS/HIV registry

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Postmortem/pathology logs, High risk pregnancy

Pediatric & tertiary care hospitals: Disease index or discharge index,

Discharge summaries, Specialty outpatient clinics

Midwifery facilities: Midwifery facilities

 ${\it Other specialty facilities:} \ {\it Prenatal diagnostic facilities (ultrasound, etc.)}$ 

Other sources: Physician reports

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codeable defect

Coding: ICD-9-CM, six-digit modified BPA/ICD-9 codes

## Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications,

Maternal risk factors

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## **Data Collection Methods and Storage**

*Data Collection*: Printed abstract/report filled out by staff, Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Natus Medical Inc.

#### Data Analysis

Data analysis software: Natus Medical Inc.

Quality assurance: Validity checks, Comparison/verification between

multiple data sources, Clinical review, none at this time

Data use and analysis: Only became active in early 2010 with review of

calendar year 2007

## **System Integration**

System links: link to Newborn Bloodspot and Hearing Screening System integration: Initial check into Newborn Bloodspot Screening records with a link that pulls info to Birth Defects Registry from Newborn Bloodspot Screening case management system.

## **Funding**

Funding Source: 100% genetic screening revenues

## Contacts

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## **District of Columbia**

District Of Columbia Birth Defects Surveillance And Prevention Program (DC BDSPP)

Purpose: Research, Referral to Services, Referral to

Prevention/Intervention *Partner*: Hospitals

Program status: Interested in developing a surveillance program

Surveillance Methods

Other state based registries: Newborn hearing screening program,

Newborn metabolic screening program

**Data Collected** 

Mother: Maternal risk factors

**Contacts** 

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## Florida

Florida Birth Defects Registry (FBDR)

*Purpose*: Surveillance, Research, Referral to Prevention/Intervention, educate health care professionals, women of childbearing age and general public about birth defects.

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, federal and state agencies

Program status: Currently collecting data

Start year: 1998

Earliest year of available data: 1998 Organizational location: Department of Health (Epidemiology/Environment), University

**Population covered annually:** 212,954 in 2012

Statewide: Yes

*Current legislation or rule*: Section 381.0031(1,2) F.S., allows for development of a list of reportable conditions. Birth defects were added

to the list in July 1999.

Legislation year enacted: 1999

Case Definition

 ${\it Outcomes\ covered} : {\it major\ structural\ malformations\ and\ selected\ genetic}$ 

disorders

Pregnancy outcome: Live Births

Age: until age 1
Residence: Florida

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based, FL has two CDC funded cooperative agreements that use active case ascertainment, which is linked to the passive surveillance program.

Vital Records: Birth certificates, Death certificates, Matched birth/death

file

Other state based registries: Programs for children with special needs

Delivery hospitals: Disease index or discharge index

Pediatric & tertiary care hospitals: Disease index or discharge index

Case Ascertainment
Coding: ICD-9-CM

Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information,

Pregnancy/delivery complications, Maternal risk factors

Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

**Data Collection Methods and Storage** 

Data Collection: Electronic file/report submitted by other agencies

(hospitals, etc.)

Database storage/management: Access, Dedicated server for birth

defects data.

Data Analysis

Data analysis software: SAS, Access, SQL, dBASE

Quality assurance: Validity checks, Comparison/verification between

multiple data sources

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, Maternal linked

*System integration:* The department has created a maternally linked file beginning with 1998. The birth defects data has been included in this linked file.

**Birth defects** data are displayed on the department's Environmental Public Health Tracking Program site.

**Funding** 

Funding Source: 62% general state funds, 34% CDC grant

Other

Web site: www.fbdr.org

Surveillance reports on file: publications, procedure manuals, electronic case ascertainment database and educational materials

Comments: CDC/NCBDDD Cooperative Agreement for enhanced

surveillance of selected birth defects, referral for services and prevention activities.

activities.

**CDC**/NCEH Cooperative Agreement for Environmental Public Health Tracking for active surveillance of selected birth defects and analysis of environmental data and birth defects.

**Contacts** 

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## Georgia

Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: Surveillance, Research

Partner: Local Health Departments, Universities, Hospitals, Advocacy

Groups, Laboratories, Prenatal Diagnostic Providers

Program status: Currently collecting data

Start year: 1967

Earliest year of available data: 1968

Organizational location: CDC, National Center on Birth Defects and

Developmental Disabilities

Population covered annually: 3,500

Statewide: No, Births to mothers residing within one of three central counties in the metropolitan Atlanta area of the state of Georgia Current legislation or rule: State Laws Official Georgia Code Annotated

(OCGA) 31-12-2

## Case Definition

*Outcomes covered*: All major structural and genetic birth defects *Pregnancy outcome*: Live Births (≥20 weeks), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective Terminations (All gestational ages)

Age: Before 6 years of age

**Residence**: Births to mothers residing in one of three central metropolitan

Atlanta counties

## Surveillance Methods

Case ascertainment: Active case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Fetal death certificates

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, induction logs and miscarriage logs

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation (birth weight < 2500 grams and/or 20- to <36 weeks gestation), All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a codeable defect

Coding: CDC coding system based on BPA

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## **Data Collection Methods and Storage**

Data Collection: Electronic file/report filled out by program staff (laptop, web-based, etc.)

Database storage/management: Access, SQL Server, SAS

## Data Analysis

Data analysis software: SPSS, SAS, Access

**Quality assurance**: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Education/public awareness, Prevention projects, survival analysis

## **System Integration**

System links: Link case finding data to final birth file, National Death Index; Death certificates, and Fetal Death certificates, Records; Laboratory Records

## **Funding**

Funding Source: 100% Intramural CDC funding

## Other

Web site: http://www.cdc.gov/ncbddd/bd/macdp.htm

Surveillance reports on file: MACDP 40th Anniversary Surveillance Report

Additional information on file: CDC/BPA Defect Code; Including prenatal diagnoses in BD monitoring

Comments: The 40th Anniversary Surveillance Report was published: *Correa* A, Cragan JD, Kucik JE, et al. Reporting birth defects surveillance data 1968-2003. Birth Defects Research Part A. 2007;79(2):65-186.

## **Contacts**

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## Georgia

Georgia Birth Defects Reporting And Information System (GBDRIS)

Program status: Interested in developing a surveillance program

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## Hawaii

Hawaii Birth Defects Program (HBDP)

*Purpose*: Surveillance, Report incidences and trends, develop preventive

strategies, develop a statewide registry

*Partner*: Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy

Groups, Legislators, Hawaii Health Data Warehouse

Program status: Currently collecting data

Start year: 1988

Earliest year of available data: 1986

Organizational location: Department of Health (Children with Special

Health Needs Branch)

Population covered annually: 18,913 (average over past 3 years)

Statewide: Yes

Current legislation or rule: HRS §321.421 to 426; HRS §321.41 to 44

Legislation year enacted: 2002

## Case Definition

Outcomes covered: All outcomes identified on the ICD-9 and CDC/BPA codes for the NBDPN Annual Report to CDC as well as other adverse neonatal conditions such as congenital infections, fetal alcohol syndrome, and specific chromosomal syndromes

*Pregnancy outcome*: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective Terminations (All gestational ages, Elective medical terminations that were carried out because a screening test or diagnostic procedure documented that the fetus was severely impaired with a birth defect, and the parents elected not to bring the baby to term)

Age: Up to one year after delivery

Residence: All in-state Hawaii births (resident and non-resident).

## Surveillance Methods

Case ascertainment: Active case ascertainment, Population based, Hospital based

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Prenatal summaries

*Pediatric & tertiary care hospitals*: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Laboratory logs

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities Other sources: Physician reports

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases, Medical terminations and spontaneous abortions where fetus was diagnosed with a birth defect, and parents elected not to bring baby to term, or mother spontaneously aborted.

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codeable defect

Coding: CDC coding system based on BPA, ICD-9-CM

## **Data Collected**

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

## Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility

(laptop, web-based, etc.)

Database storage/management: Access

## Data Analysis

Data analysis software: SAS, Access

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple

data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Grant proposals, Education/public awareness, Prevention projects, State Surveillance Data Report

#### **Funding**

Funding Source: 100% Birth Defects Special Fund (state fund from marriage license fee)

## Other

Web site: http://hawaii.gov/health/family-child-

health/genetics/hbdhome.html

Surveillance reports on file: Thirteen HBDP Statewide Surveillance Data Reports: (1) 1989-1991, (2) 1988-1993, (3) 1988-1994, (4) 1988-1995, (5) 1987-1996, (6) 1986-1997, (7) 1986-1998, (8) 1986-1999, (9) 1986-2000, (10) 1986-2001, (11) 1986-2002, (12) 1986-2003, (13) 1986-2005. Additional information on file: Hawai'i Statutory Authority; HBDP Publications; HBDP Case finding list; HBDP BPA Codes

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## Idaho

Program status: No surveillance program

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#### Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Purpose: Surveillance, Referral to Services, Prevention/Intervention Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, State agency serving children with special healthcare needs

Program status: Currently collecting data

Start year: 1986

Earliest year of available data: 1989

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 165,000

Statewide: Yes

Current legislation or rule: Illinois Health and Hazardous Substances

Registry Act (410 ILCS 525) Legislation year enacted: 1985

## Case Definition

Outcomes covered: ICD-9-CM Codes 740.0 through 759.9; infants positive for controlled substances; very low birth weight (< 1500g); fetal death; death during the newborn hospital stay; serious congenital infections; congenital endocrine, metabolic or immune disorders; congenital blood disorders; other conditions such as retinopathy of prematurity, intrauterine growth retardation, FAS

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Up to 2 years of age

Residence: In and out of state births to state residents

## Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population based, Hospital based

Vital Records: Birth certificates, Fetal death certificates

Other state based registries: Newborn metabolic screening program Delivery hospitals: Disease index or discharge index, Discharge summaries, hospitals mandated to identify and report newborn cases Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, hospitals mandated to report newborns discharged from any of the NICU or specialty units

Other specialty facilities: Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), All neonatal deaths

Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: Modified CDC/BPA coding system

## **Data Collected**

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

## **Data Collection Methods and Storage**

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic

file/report submitted by other agencies (hospitals, etc.) Database storage/management: Access, Mainframe

## Data Analysis

Data analysis software: SAS, Access, Arc Map, JoinPoint Ouality assurance: Validity checks, Re-abstraction of cases, Doublechecking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, Public Use Data Set

## **System Integration**

System links: Link case finding data to final birth file

System integration: The APORS program data is incorporated into a data warehouse at the Illinois Department of Healthcare and Family Services.

## Funding

Funding Source: 75% general state funds, 25% Service fees

Web site: www.idph.state.il.us/about/epi/apors.htm

Surveillance reports on file: Surveillance reports are available on-line -visit website listed above, as are public use data sets.

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## Indiana

Indiana Birth Defects & Problems Registry (IBDPR)

Purpose: Surveillance, Research, Referral to Services

Partner: Universities, Hospitals, Early Childhood Prevention Programs,

Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 2002

Earliest year of available data: 2003 birth data is available in 2006

Organizational location: Department of Health

(Epidemiology/Environment), Department of Health (Maternal and Child

Health), Department of Health (State Health Data Center)

Population covered annually: 89,000

Statewide: Yes

Current legislation or rule: IC 16-38-4-7, Rule 410 IAC 21-3

Legislation year enacted: 2001

## Case Definition

Outcomes covered: ICD-9-CM Codes 740-759.9, Fetal Alcohol Spectrum Disorder (760.71), Pervasive Developmental Disorder (299.0), fetal deaths, metabolic disorders & hearing loss from newborn screening, selected neoplasms, congenital blood disorders, and certain eye disorders. Pregnancy outcome: Live Births (All gestational ages and birth weights) Age: up to 5 years (FAS, autism); up to 3 years for all other birth defects Residence: In- and out-of-state (as reported to IBDPR) births to state residents

## Surveillance Methods

Case ascertainment: Combination of active and passive case

ascertainment, Hospital based

Vital Records: Birth certificates, Death certificates, Matched birth/death

file

Other state based registries: Newborn hearing screening program,

Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Chart audits of 45

targeted birth defects

Pediatric & tertiary care hospitals: Disease index or discharge index,

Chart audits of 45 targeted birth defects

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759

Conditions warranting chart review beyond the newborn period: Any

infant with a codeable defect *Coding*: ICD-9-CM, and BPA

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## **Data Collection Methods and Storage**

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), ISDH Chart Auditors submit hospital chart audit information electronically through use of a laptop and a web-based portal to the Indiana State Department of Health Repository, which stores and integrates the data.

Database storage/management: Oracle

## Data Analysis

Data analysis software: SAS, Oracle and ArcView GIS Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Needs assessment

## **System Integration**

System links: Link to other state registries/databases, Link case finding data to final birth file

System integration: The database is linked with birth, death, newborn hearing screening, and newborn metabolic screening data.

## Funding

Funding Source: 20% MCH funds, 80% From the IBDPR fund obtained through birth certificate sales.

## **Other**

Web site: www.birthdefects.in.gov

## Contacts

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#### Iowa

Iowa Registry For Congenital And Inherited Disorders (IRCID)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Prevention education programs
Partner: Local Health Departments, Universities, Hospitals,

Environmental Agencies/Organizations, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1983

Earliest year of available data: 1983 Organizational location: University

Population covered annually: 37,831 average 10 year

Statewide: Ye

Current legislation or rule: Iowa Code 136A, Iowa Administrative Code

641-4.7

Legislation year enacted: 1986; Revised 2001, 2003, 2004, 2009, 2013

## Case Definition

*Outcomes covered*: major birth defects, Duchenne/Becker, congenital, distal, Emery-Dreifuss, fascioscapulohumeral, limb-girdle, myotonic, and oculopharyngeal muscular dystrophies, fetal deaths with and without birth defects, newborn screening disorders

*Pregnancy outcome*: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective Terminations (All gestational ages)

Age: 1 year

Residence: maternal residence in Iowa at time of delivery

## Surveillance Methods

Case ascertainment: Active case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Fetal death certificates, Fetal Death Evaluation Protocol

*Other state based registries*: Programs for children with special needs, Development Disabilities Surveillance, Cancer registry, AIDS/HIV registry, Iowa Perinatal Care Program

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Collect verbatim summaries of surgical reports, diagnostic test results, consultation reports, and autopsy/surgical pathology reports

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Collect verbatim summaries of surgical reports, diagnostic test results, consultation reports, and autopsy/surgical pathology reports

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: Physician reports, Outpatient surgery facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases, muscular dystrophy

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codeable defect

Coding: CDC coding system based on BPA, ICD-9-CM

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## Data Collection Methods and Storage

**Data Collection**: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database storage/management: Access, Oracle, PC server

## Data Analysis

Data analysis software: SPSS, SAS, Access, Oracle

*Quality assurance*: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Capture-recapture analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

## **System Integration**

System links: Link case finding data to final birth file, Link to environmental databases. For specific studies, data may be linked with environmental databases or other state databases.

## **Funding**

Funding Source: 35% general state funds, 65% CDC grant

## **Contacts**

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## Kansas

Birth Defects Information System (BDIS)

Purpose: Registry
Partner: Hospitals

Program status: Interested in developing a surveillance program

Start year: 1985

Earliest year of available data: 1985

Organizational location: Department of Health

(Epidemiology/Environment), Department of Health (Vital Statistics),

Department of Health (Maternal and Child Health) *Population covered annually*: 39,628 (Year 2011)

Statewide: Yes

Current legislation or rule: K.S.A. 65-1,241 through 65-1,246

Legislation year enacted: 2004

## Case Definition

Outcomes covered: The outcome data below are available from Office of Vital Statistics. Live births and stillbirths (fetal deaths) information are used as part of the Birth Defects Information System (BDIS). Thirteen anomalies (and "other" congenital anomalies) are listed on the birth certificate and are reported, however, these are not linked to ICD-9 codes. In addition to major birth defects, low birth weight and low Apgar scores are also reported to BDIS.

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (greater than 350 grams)

Age: Under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition.

**Residence**: In state and out of state births to Kansas residents and in-state births to out of state residents

## Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based

Vital Records: Birth certificates, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening

program

Other sources: Physician reports

## <u>Case Ascertainment</u> <u>Coding</u>: ICD-9-CM

## **Data Collected**

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.)

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Maternal risk factors

*Father*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

## **Data Collection Methods and Storage**

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), In Kansas, birth defects (congenital anomalies) are collected through three data sources: live birth certificates, stillbirth (fetal death) certificates, and the congenital malformations and fetal alcohol syndrome reporting form. The live birth and stillbirth (fetal death) certificates data (congenital anomalies and abnormal conditions) contained within the Vital Statistics Integrated Information System are extracted, downloaded and transferred to BDIS. Any additional reports of congenital anomalies from physicians, hospitals and freestanding birthing centers are entered manually into BDIS.

Database storage/management: Access, SQL Server

## Data Analysis

Data analysis software: SAS

**Quality assurance**: Comparison/verification between multiple data sources, Office of Vital Statistics conducts verification on live birth and stillbirth (fetal death) certificate data.

*Data use and analysis*: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Grant proposals, ad-hoc upon request

## System Integration

System links: Link to other state registries/databases

System integration: Our program has a link with vital statistics records. BDIS uses the same data system (WebBFH) and shares information with Children and Youth with Special Health Care Needs and Newborn metabolic screening program.

## **Funding**

Funding Source: 100% MCH funds

## Other

Web site: http://www.kdheks.gov/bfh/birth\_defects.htm

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## Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention, Prevention of birth defects

**Partner**: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention

Programs, Advocacy Groups, Legislators **Program status**: Currently collecting data

Start year: 1996

Earliest year of available data: 1998

*Organizational location*: Department of Health (Maternal and Child Health), Department for Public Health, Division of Maternal and Child

Health, Early Childhood Development Branch

Population covered annually: 56,000

Statewide: Yes

Current legislation or rule: KRS 211.651-211.670

Legislation year enacted: 1992

## Case Definition

*Outcomes covered*: major birth defects, genetic diseases, fetal mortality *Pregnancy outcome*: Live Births (All gestational ages and birth weights) Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, 20 weeks or 350 grams)

Age: up to fifth birthday

Residence: all in-state births; out of state births to state residents

## Surveillance Methods

Case ascertainment: Combination of active and passive case

*Vital Records*: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, medical laboratory reporting mandated; outpatient reporting voluntary

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Specialty outpatient clinics, laboratory records

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, laboratory records Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Other sources: Physician reports, local health departments

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g., seizure), Cardiovascular condition, Any infant with a codeable defect Coding: ICD-9-CM, ICD-10 for Vital Statistics death data

## **Data Collected**

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## Data Collection Methods and Storage

**Data Collection**: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access

## Data Analysis

Data analysis software: SAS, Access, Link Plus

 ${\it Quality~assurance} \colon \hbox{Re-abstraction~of~cases, Double-checking~of~assigned}$ 

codes, Comparison/verification between multiple data sources,

Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, IRB-approved research projects

## **System Integration**

System links: Link case finding data to final birth file System integration: True positives identified by newborn screening are integrated into the KBSR database.

## Funding

Funding Source: 40% general state funds, 60% Service fees

Other

Web site: http://chfs.ky.gov/dph/ach/ecd/kbsr.htm

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## Louisiana

Louisiana Birth Defects Monitoring Network (LBDMN)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention

Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 2005

Earliest year of available data: 2005

Organizational location: Department of Health Title V CYSHCN

Programs

Population covered annually: approx. 61,000 (2009)

Statewide: Yes

Current legislation or rule: Law: LA R.S. 40:31.41 - 40:31.48, 2001.

DHH Rule: LAC 48:V.Chapters 161 and 163

Legislation year enacted: 2001

Case Definition

Outcomes covered: major structural birth defects and selected genetic

diseases

*Pregnancy outcome*: Live Births ( $\geq 20$  weeks or  $\geq 350$  grams)

Age: up to three years old

Residence: in- and out-of-state births to state residents

Surveillance Methods

Case ascertainment: Combination of active and passive case

ascertainment, Population based

Vital Records: Birth certificates, Matched birth/death file Delivery hospitals: Disease index or discharge index, Discharge

summaries, ICU/NICU logs or charts

Pediatric & tertiary care hospitals: Disease index or discharge index,

Discharge summaries, ICU/NICU logs or charts

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM

codes outside 740-759

Conditions warranting chart review beyond the newborn period: Any

infant with a codeable defect

Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar score, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information,

Pregnancy/delivery complications, Maternal risk factors, Family history *Father*: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

**Data Collection Methods and Storage** 

*Data Collection*: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic scanning of printed records, Hand-

written, printed forms phased out in 2011.

Database storage/management: Access, Excel, InfoPath/SharePoint

stored in SQL

Data Analysis

Data analysis software: SAS, Access, GIS

Quality assurance: Validity checks, Re-abstraction of cases, Comparison/verification between multiple data sources, Timeliness Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Education/public awareness, Prevention projects

**System Integration** 

System links: Link case finding data to final birth file, link case finding

data to infant death file

System integration: Integration with Louisiana Electronic Event

Registration System (LEERS) birth and death records will be completed

by January 2014.

**Funding** 

Funding Source: 28% CDC grant, 72% Title V CSHCN funds

**Other** 

Web site: www.dhh.la.gov/lbdmn

Surveillance reports on file: Louisiana Morbidity Report, May-June 2009, Vol 20, No 3; Results from Louisiana 2006-2008 Birth Defects Surveillance System, A poster presented at 2013 NBDPN Annual Meeting in Atlanta; 2005-2008 linked birth defects and birth records data; Maps of 12 major birth defects by region and parish created by EPHT

using 2006-2008 linked birth defects and birth records data **Additional information on file**: Advisory Board Documentation

Comments

http://wwwprd.doa.louisiana.gov/boards and commissions/viewBoard.cfm

?board=192

Contacts

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## Maine

Maine CDC Birth Defects Program (MBDP)

 ${\it Purpose} \hbox{: Surveillance, Research, Referral to Services, Referral to}$ 

Prevention/Intervention, Education

Partner: Universities, Hospitals, Community Nursing Services,Environmental Agencies/Organizations, Early Childhood PreventionPrograms, Advocacy Groups, March of Dimes, New Hampshire Birth

Conditions Program

Program status: Currently collecting data

Start year: 1999

Earliest year of available data: 2003

Organizational location: Department of Health (Division of Population

Health/MCH Unit/CSHN)

Population covered annually: 12, 593

Statewide: Yes

Current legislation or rule: 22 MRSA c. 1687

Legislation year enacted: 1999

## Case Definition

*Outcomes covered*: Selected major birth defects: NTD, clefts, gastroschisis, omphalocele, trisomy 21, reduction deformities of upper and lower limb, hypospadias and major heart defects

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, prenatally diagnosed at any gestation), Elective Terminations (prenatally diagnosed at any gestation)

Age: Through age one

Residence: All in-state births to Maine residents

## Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based, Passive case ascertainment with active case confirmation

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening

program

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

*Pediatric & tertiary care hospitals*: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Specialty outpatient clinics

Midwifery facilities: Midwifery facilities

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: Physician reports, Children with Special Health Needs

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period:

Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a codeable defect

Coding: CDC coding system based on BPA, ICD-9-CM

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

## Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records

Database storage/management: Oracle, Microsoft SQL Server

## Data Analysis

Data analysis software: SAS, Stat-exact

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

## **System Integration**

System links: Link to other state registries/databases, Link case finding data to final birth file

System integration: Newborn Hearing/ Newborn Bloodspot Screening Programs

## Funding

Funding Source: 85% MCH funds, 15% Maine Environmental Public Health Tracking grant

## Other

 $\textit{Web site}: http://www.maine.gov/dhhs/boh/cshn/birth\_defects/index.html$ 

## Contacts

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## Maryland

Maryland Birth Defects Reporting and Information System (BDRIS)

Purpose: Surveillance, Referral to Services

**Partner**: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention

Programs, Advocacy Groups, Legislators **Program status**: Currently collecting data

Start year: 1983

Earliest year of available data: 1984

Organizational location: Department of Health

(Epidemiology/Environment), Department of Health (Prevention and

Health Promotion Administration) *Population covered annually*: 75,000

Statewide: Yes

Current legislation or rule: Health-General Article, Section 18-206;

Annotated Code of Maryland *Legislation year enacted*: 1982

## Case Definition

Outcomes covered: Selected birth defects - anencephaly, spina bifida, hydrocephaly, cleft lip, cleft palate, esophageal atresia/stenosis, rectal/anal atresia, hypospadias, reduction deformity - upper or lower limb, congenital hip dislocation, and Down syndrome until 2009, then all significant birth defects

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, or ≥ 500 grams weight; reports accepted on fetal deaths <500 grams or <20 weeks gestation if sent to us); reports accepted on terminations <500 grams or <20 weeks gestation if sent to us; BDRIS has no specific legal authority to collect information on terminations. Maryland does not require that any certificate be filed with Vital Records

for a termination unless the body is transported for burial.

Age: Newborn

Residence: all in-state births

## Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Sickle Cell Disease, Critical Congenital Heart Defect follow Up Program

Delivery hospitals: primary source: sentinel birth defects hospital report

form; electronic reporting began 5/1/13 *Midwifery facilities*: Midwifery facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: All fetal death certificates

Coding: ICD-9-CM

## **Data Collected**

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth

measurements (weight, gestation, Apgar, etc.), Tests and procedures, Birth defect diagnostic information

**Mother**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history **Father**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## **Data Collection Methods and Storage**

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic

reporting began 5/1/13

*Database storage/management*: Access, Mainframe, Visual dBASE, SAS, ASCII files; as of 5/1/13 data stored on vendor server

## Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Double-checking of assigned codes,

Comparison/verification between multiple data sources

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Service delivery, Referral, Grant proposals, Education/public

## **System Integration**

*System integration*: As of 5/1/13, the birth defects data collection is integrated into the same electronic system in which we collect hearing and CCHD screening data.

## **Funding**

Funding Source: 100% general state funds

## Other

Web site: http://phpa.dhmh.maryland.gov/genetics/SitePages/bdris.aspx Surveillance reports on file: All reports submitted to CDC

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## Massachusetts

Birth Defects Monitoring Program, Massachusetts Center For Birth Defects Research And Prevention, Massachusetts Department Of Public Health (MBDMP)

Purpose: Surveillance, Research, Referral to Prevention/InterventionPartner: Universities, Hospitals, Environmental Agencies/Organizations,

Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1997

Earliest year of available data: 1999 for statewide data

Organizational location: Department of Public Health (Bureau of Family

Health and Nutrition)

Population covered annually: 73,000

Statewide: Yes

*Current legislation or rule*: Massachusetts General Laws, Chapter 111, Section 67E. In 2002 the Massachusetts Legislature amended this statute, expanding the birth defects monitoring program. Regulations (105 CMR 302.000) were promulgated on February 6, 2009.

Legislation year enacted: 1963

## Case Definition

*Outcomes covered*: Major structural birth defects and chromosomal anomalies of medical, surgical or cosmetic significance

**Pregnancy outcome**: Live Births (All gestational ages and birth weights) Fetal deaths - stillbirths, spontaneous abortions, etc. (Reportable fetal

deaths: ≥20 weeks gestation or ≥350 grams)

Age: Up to one year

Residence: In and out-of-state births to state residents

## Surveillance Methods

Case ascertainment: Combination of active and passive case

ascertainment, Population based

Vital Records: Birth certificates, Death certificates, Fetal death

certificates

*Delivery hospitals*: Disease index or discharge index, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts,

Postmortem/pathology logs

Pediatric & tertiary care hospitals: Disease index or discharge index, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), All stillborn infants. All neonatal deaths

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, GI condition (e.g. recurrent blockage), Ocular conditions, Cardiovascular condition, All infant deaths (excluding prematurity), Auditory/hearing conditions, Any infant with a codeable defect

Coding: CDC coding system based on BPA

## Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity,

Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history *Father*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records, Data from Confidential Reporting and Abstracting Form is entered into electronic surveillance database based on paper or electronic records (laptops).

Database storage/management: Access

## Data Analysis

Data analysis software: SAS, Access, Excel

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness, 1) selected cases from surveillance are eligible for CDCs National Birth Defects Prevention Study 2) contributed data to other surveillance research projects

## System Integration

*System links*: 1) link case finding data to final birth file, 2) Link case finding data to final fetal death file, 3) Massachusetts Pregnancy to Early Life Longitudinal (PELL) Data System

## **Funding**

Funding Source: 28% general state funds, 72% MCH funds

## Other

Web site: http://www.mass.gov/dph/birthdefects

Surveillance reports on file: go to http://www.mass.gov/dph/birthdefects to view or download annual surveillance reports.

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## Michigan

Michigan Birth Defects Registry (MBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, prevalence and mortality statistics
 Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1992

Earliest year of available data: 1992

Organizational location: Department of Health (Vital Statistics)

Population covered annually: 112,000

Statewide: Yes

Current legislation or rule: Public Act 236 of 1988

Legislation year enacted: 1988

## Case Definition

*Outcomes covered*: Congenital anomalies, certain infectious diseases, conditions caused by maternal exposures and other diseases of major organ systems

*Pregnancy outcome*: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks or >400 grams)

Age: up to two years after delivery except that reporting to age 12 for FASD beginning in 2013

**Residence**: Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

## Surveillance Methods

Case ascertainment: Passive case ascertainment, Combination of active and passive case ascertainment, Population based

*Vital Records*: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Fetal deaths since 2004 only

*Other state based registries*: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry

**Delivery hospitals**: Disease index or discharge index, Specialty outpatient clinics

**Pediatric & tertiary care hospitals**: Disease index or discharge index, Specialty outpatient clinics

Third party payers: Medicaid databases, CSHCS Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), GU condition (e.g., recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Ocular conditions, Auditory/hearing conditions, Any infant with a codeable defect

Coding: ICD-9-CM

## **Data Collected**

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors

Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

## **Data Collection Methods and Storage**

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.) Electronic Birth Certificate birth defects reporting module

Database storage/management: Fox-pro

## Data Analysis

Data analysis software: SPSS, Access, Fox-pro, Excel

*Quality assurance*: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

## **System Integration**

System links: Link to other state registries/databases, Link case finding data to final birth file, CSHCS, WIC

System integration: No, data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures.

## **Funding**

Funding Source: 10% Service fees, 90% Vital Records Fees

## **Other**

Web site: http://www.michigan.gov/mdch/0,1607,7-132-2944\_4670---

## Additional information on file:

http://www.michigan.gov/mdch/0,1607,7-132-2945\_5221-16665-,00.html

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### Minnesota

Minnesota Birth Defects Information System (BDIS)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention

Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 2005

Earliest year of available data: 2006

Organizational location: Department of Health (Community & Family

Health)

Population covered annually: 70,000

Statewide: No, Prevalence estimates are available for the two largest counties in Minnesota, Hennepin and Ramsey counties, which account for just under 50% of MN births. The surveillance system has been gradually expanding and is currently covering about 82% of live births. Statewide surveillance is expected to be completed by the end of 2013.

Current legislation or rule: MS 144.2215-2219

Legislation year enacted: 2004

### Case Definition

*Outcomes covered*: Major structural and genetic defects diagnosed up to 1 year of age identified by CDC and NBDPN

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: up to 1 year after delivery

Residence: In-state and out of state births to state residents

### Surveillance Methods

Case ascertainment: Active case ascertainment, Combination of active and passive case ascertainment, Population based

Vital Records: Birth certificates, Death certificates, Matched birth/death file

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program; Beginning in 2013, newborn CCHD screening program

**Delivery hospitals**: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics

*Pediatric & tertiary care hospitals*: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics

Third party payers: Medicaid databases

Other sources: Statewide de-identified hospital discharge dataset

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked. Starting with 2009 births, all deaths prior to age 2 with a birth defect indicated as cause of death on death certificates

Coding: CDC coding system based on BPA

## **Data Collected**

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Family history

## **Data Collection Methods and Storage**

**Data Collection**: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report filled out by staff off-site using remote access to EMRs or PDF files of EMRs.

**Database storage/management**: Web-based department-wide integrated disease surveillance database. Maven platform by Consilience Software.

### Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Data/hospital audits, Clinical review,

Timeliness, Physician review as needed

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Collaboration with Environmental Public Health Tracking Program. Additional analyses will be conducted when sufficient data are available. Surveillance should be statewide by the end of 2013.

## **System Integration**

System links: Link to other state registries/databases, Link case finding data to final birth file, Sharing of confirmed cases with key contacts at local public health agencies for service referral. LPH staff can log on to the birth defects database to view relevant case information. In 2012, LPH began entering follow up and service/program updates into BDIS. System integration: BDIS is integrated with Newborn Hearing program. The databases share a model on the same platform, but they are managed separately. (This platform, Maven by Consilience Software, is also used by many infectious disease surveillance systems in MN and access is limited by disease/user role.) Additional integration with the Newborn Screening program will take place in 2013 as universal newborn CCHD screening is implemented.

## **Funding**

Funding Source: 85% general state funds, 15% CDC grant

## Other

Web site: http://www.health.state.mn.us/birthdefects

Additional information on file: Folic Acid Guidelines for physicians

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## Mississippi

Mississippi Birth Defects Surveillance Registry (BDRS)

Purpose: Surveillance

Partner: Local Health Departments, Hospitals, Title V Children with

Special Health Care Needs

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2000

Organizational location: Department of Health (Maternal and Child

Health), Department of Health (Genetic Services Bureau)

Population covered annually: 42,000

Statewide: Yes

Current legislation or rule: Section 41-21-205 of the Mississippi Code of

1972

Legislation year enacted: 1997

Case Definition

*Outcomes covered*: Live births and reportable fetal deaths with birth defects (fetal death of 20 completed weeks of gestation or more, or a weight of 350 grams or more) shall be reported.

weight of 550 grains of more) shan be reported.

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation

and greater, or 350 grams or more)

Age: Birth to 21 years

Residence: in state and out of state births to residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based

Vital Records: Birth certificates, Death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening

program

Delivery hospitals: Disease index or discharge index, Discharge

summaries

Pediatric & tertiary care hospitals: Disease index or discharge index,

Discharge summaries, Specialty outpatient clinics

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment
Coding: ICD-9-CM

**Data Collected** 

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth

measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic

information

Mother: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

**Data Collection Methods and Storage** 

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic

abstract/report submitted by other agencies (hospitals, etc.), Electroni file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access

Data Analysis

Data analysis software: SPSS, SAS, Access

Quality assurance: Validity checks, Double-checking of assigned codes,

Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates,

Rates by demographic and other variables, Needs assessment,

Education/public awareness

**Funding** 

Funding Source: 100% genetic screening revenues

**Other** 

Web site: www.healthyms.com

Surveillance reports on file: Birth Defects Surveillance Report 2000-

2007

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### Missouri

Missouri Birth Defects Surveillance System

Purpose: Surveillance, Research

Partner: Environmental Agencies/Organizations, Legislators

Program status: Currently collecting data

Start year: 1985

Earliest year of available data: 1980

Organizational location: Department of Health (Vital Statistics)

Population covered annually: 79,000

Statewide: Yes

Case Definition

Outcomes covered: ICD9 codes 740-759, plus genetic, metabolic, and

other disorders

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation

and greater, Fetal death certificates are only source of data)

Age: up to one year after delivery

Residence: in- and out-of -state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Matched birth/death

file, Fetal death certificates

Delivery hospitals: Discharge summaries

Pediatric & tertiary care hospitals: Discharge summaries, Specialty

outpatient clinics

Case Ascertainment

Coding: ICD-9-CM, ICD-10

Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures,

Infant complications, Birth defect diagnostic information

**Mother**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Pregnancy/delivery complications, Maternal risk factors **Father**: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

**Data Collection**: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other

agencies (hospitals, etc.)

Database storage/management: SAS

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Double-checking of assigned codes,

Comparison/verification between multiple data sources

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Education/public

awareness

**System Integration** 

System links: Link case finding data to final birth file

**Funding** 

Funding Source: 100% MCH funds

**Other** 

Web site: http://health.mo.gov/data/birthdefectsregistry/index.php Surveillance reports on file: MO Birth Defects Report 1996-2000

Contacts

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### Montana

Montana Birth Outcomes Monitoring System (MBOMS)

Purpose: Surveillance, Referral to Services
Partner: private practice physicians
Program status: No surveillance program

Start year: 1999

Earliest year of available data: 2000

Organizational location: Department of Health (Maternal and Child

Health)

Population covered annually: ~12,000

Statewide: Yes

Current legislation or rule: none

## Case Definition

*Outcomes covered*: major structural birth defects, chromosomal anomalies specified in the CDC 45 reportables for births occurring in calendar years 2000 through 2004. Registry suspended beginning with calendar year 2005 births due to loss of CDC funding.

Pregnancy outcome: all gestational ages

## **Funding**

Funding Source: No funding available since 8/26/2005

#### Other

**Comments**: Due to lack of funding, Montana is no longer performing active surveillance. Informal active/passive surveillance continues and linkages between ascertainment and services are in place and supported. Data and program linkages exist between newborn hearing screening, birth certificates, and newborn screening.

## Contacts

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### Nebraska

Nebraska Birth Defects Registry

Purpose: Surveillance, We are in the process of exploring our policy on

expanding the use of the birth defects data

Partner: Hospitals, Early Childhood Prevention Programs, Nebraska Department of Health and Human Services, Vital Statistics and MCH

Program status: Currently collecting data

Start year: 1973

Earliest year of available data: 1973

*Organizational location*: Department of Health (Vital Statistics), Department of Health (Nebraska Department of Health and Human

Services, Public Health, Office of Health Statistics)

Population covered annually: Statewide, 26,000 births annually

Statewide: Yes

Current legislation or rule: Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health and Welfare [Codes] §71-645, §71-646,

§71-647, §71-648, §71-649) *Legislation year enacted*: 1972

Case Definition

Outcomes covered: All birth defects, exclusions according to CDC

exclusion list

*Pregnancy outcome*: Live Births (Greater than 20 weeks and greater than 500 grams), Fetal deaths - stillbirths, spontaneous abortions, etc. (20

weeks gestation and greater)

Age: Birth to 1 year

Residence: In-state and out-of-state births to state residents.

Surveillance Methods

Case ascertainment: Passive case ascertainment

Vital Records: Birth certificates, Death certificates, Fetal death

certificates

Other state based registries: Newborn hearing screening program,

Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Discharge

summaries, ICU/NICU logs or charts

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient

clinics

Midwifery facilities: Midwifery facilities

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: We are a passive system and don't conduct chart reviews on any conditions in

newborn period and beyond the newborn period Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic information

**Mother**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity **Father**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

### **Data Collection Methods and Storage**

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other

agencies (hospitals, etc.)

Database storage/management: SQL

Data Analysis

Data analysis software: SAS, Reports from Netsmart.

*Quality assurance*: Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Case

finding, data coding and entry.

Data use and analysis: Baseline rates, Monitoring outbreaks and cluster investigation, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Incidence rates, trend analysis, birth defect registry.

System Integration

System links: Birth

System integration: Integrated with births, fetal deaths, deaths and

hearing screening.

**Funding** 

Funding Source: 100% MCH funds

**Other** 

Web site:

 $http://dhhs.ne.gov/publichealth/Pages/vitalrecords\_partners.aspx$ 

Surveillance reports on file:

http://dhhs.ne.gov/publichealth/Pages/ced\_vs.aspx

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## Nevada

Nevada Birth Outcomes Monitoring System (NBOMS)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

Partner: Hospitals, Early Childhood Prevention Programs, Legislators,

Bureau of Child, Family, & Community Wellness *Program status*: Currently collecting data

Start year: 2000

Earliest year of available data: 2005

Organizational location: Department of Health (Maternal and Child Health), State Health Division, Office of Health Statistics and Surveillance, Bureau of Health Statistics, Planning, Epidemiology and

Response

Population covered annually: About 35,000

Statewide: Yes

Current legislation or rule: NRS 442.300 - 442.330 - Birth Defects

Registry Legislation \*\*\* Regulation = NAC 442

Legislation year enacted: 1999

## Case Definition

Outcomes covered: Major birth defects and genetic diseases

*Pregnancy outcome*: Live Births (20 weeks of gestation and greater with all birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective Terminations (20 weeks gestation and greater)

*Age*: Birth to 7 years of age *Residence*: In-state births

## Surveillance Methods

Case ascertainment: Combination of active and passive case

ascertainment, Population based, Hospital based

Vital Records: Birth certificates, Death certificates, Matched birth/death

file, Fetal death certificates, hospital medical records,

diagnostic/laboratory reports

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index,

Discharge summaries

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any birth certificate with a birth defect box checked

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), GU condition (e.g., recurrent infections), Cardiovascular condition, Any infant with a codeable defect

Coding: ICD-9-CM

## **Data Collected**

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth

measurements (weight, gestation, Apgar, etc.), Tests and procedures,

Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery

complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions,

Family history

## Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff

Database storage/management: Access

### Data Analysis

Data analysis software: SAS, Access

Quality assurance: Double-checking of assigned codes,

Comparison/verification between multiple data sources, Data/hospital

audits, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

## **System Integration**

System links: Link to other state registries/databases, Birth registry data is manually linked to birth defect data, but the actual databases are not linked.

## Funding

Funding Source: 100% MCH Block Grant

## Other

## Surveillance reports on file:

 $http://health.nv.gov/PUBLICATIONS/OHSS/2009\_NBOMS\_Annual\_Report.pdf$ 

## **Contacts**

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## **New Hampshire**

New Hampshire Birth Conditions Program (NHBCP)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention

Programs, Advocacy Groups, Legislators **Program status**: Currently collecting data

Start year: 2003

Earliest year of available data: 2003

Organizational location: Department of Health (Maternal and Child Health), Department of Health (Bureau of Special Medical Services: Bureau of Nutrition and Health Promotion, Department of Environmental

Services Bureau of Environmental Health), University

Population covered annually: 12,500

Statewide: Yes

Current legislation or rule: RSA 141:J, NH Administrative Rules He-P

3012

Legislation year enacted: 2008

## Case Definition

Outcomes covered: all major birth defects and genetic diseases recommended by the CDC/NBDPN

*Pregnancy outcome*: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective Terminations (All gestational ages)

Age: Currently collecting birth to age 2

Residence: all New Hampshire residents, in-state and out-of-state

### Surveillance Methods

Case ascertainment: Active case ascertainment, Population based Vital Records: Birth certificates, Fetal death certificates, Elective termination certificates, hospital ICD-9 codes for admissions, discharges and transports, fetal pathology reviews at Dartmouth Hitchcock Medical Center

Other state based registries: Programs for children with special needs, Newborn hearing screening program

 $\label{eq:Delivery hospitals: Discharge summaries, Obstetrics logs (i.e., labor \& delivery), Regular nursery logs, ICU/NICU logs or charts,$ 

Postmortem/pathology logs, Specialty outpatient clinics, medical records abstraction of charts of selected ICD 9 Codes

Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, cytogenetics laboratory, perinatal pathology logs, Medical Genetics Clinic files, molecular genetics laboratory, Prenatal Diagnosis Program files

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, elective terminations that have confirmed birth conditions by autopsy or confirmed by clinical assessment

Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: CDC coding system based on BPA, ICD-9-CM

### Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history *Father*: Identification information (name, address, date-of-birth, etc.)

## Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database storage/management: Oracle, AURIS, a web-based reporting system currently utilized by the NH DHHS Newborn Hearing Screening Program, has added a module to the currently operating system to meet the birth defects tracking requirements.

#### Data Analysis

Data analysis software: SPSS, Access

*Quality assurance*: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Observed vs. expected analyses, Epidemiologic studies (using only program data), Service delivery, Grant proposals, Education/public awareness, Prevention projects

## **System Integration**

System links: Link to other state registries/databases

System integration: Integrated into the NH DHHS Newborn Hearing Screening Program registry, a statewide universal hearing program for all NH infants. This system also receives weekly uploads from the State's Vital Records system that is then linked with the birth conditions and newborn screening data. In addition, in 2011 the NH Birth Conditions Program database was linked with the Title V program database with data on children receiving Special Medical Services in NH.

## Funding

Funding Source: 100% CDC grant

<u>Other</u>

Web site: www.nhbcp.org

## Contacts

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### **New Jersey**

Special Child Health Services Registry (SCHS REGISTRY)

**Purpose**: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Neurodevelopmental Centers; Federally Qualified Health Care Centers;

State Parent Advocacy Network

Program status: Currently collecting data

Start year: 1928

Earliest year of available data: 1985

Organizational location: Department of Health - Special Child Health and

Early Intervention Services

Population covered annually: 110,000

Statewide: Yes

Current legislation or rule: NJSA 26:8-40.20 et seq., NJAC 8:20 - Amended: 1990, 1991, 1992, 2005, Readopted: 2010, Rule Amendments

Adopted: 2009; Re-adopted 2010 *Legislation year enacted*: 1983

### Case Definition

*Outcomes covered*: All birth defects (structural, genetic, and biochemical), all Autism Spectrum Disorders, and severe hyperbilirubinemia, are required to be reported; all special needs and any condition which places a child at risk (prematurity, asthma, cancer, developmental delay) are also reported but not required.

**Pregnancy outcome**: Live Births (All gestational ages and birth weights) **Age**: mandated reporting of birth defects diagnosed through age 5, voluntary reporting of birth defects diagnosed > age 6 and all children diagnosed with Special Needs conditions who are 22 years or younger **Residence**: all NJ residents, in and out of state

## Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population based

Vital Records: Birth and death certificates, Matched birth/death file Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Autism Registry

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, quality assurance visit consisting of chart review of 3 month period

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics, quality assurance visit consisting of chart review of 3 month period

Midwifery facilities: Midwifery facilities

Third party payers: Universal Billing database is used for Quality

Assurance activities

Other specialty facilities: Cytogenetic laboratories, Genetic

counseling/clinical genetics facilities

*Other sources*: Physician reports, Special Child Health Services county based Case Management units, parents, medical examiners. Autism diagnosticians and treatment centers.

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, All neonatal deaths, all death certificates for < 3 years old Conditions warranting chart review beyond the newborn period: GI condition (e.g., recurrent blockage), GU condition (e.g., recurrent

infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codeable defect *Coding*: ICD-9-CM

### Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic information Mother: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

## **Data Collection Methods and Storage**

*Data Collection*: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), implementation of a web-based reporting ongoing since July 1, 2009

Database storage/management: Mainframe, SAS; SQL

### Data Analysis

Data analysis software: SAS, Access

**Quality assurance**: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness, merge registry with birth certificate registry and the death certificate registry

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

## System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, link to hearing screening registry

System integration: Autism Registry is fully integrated. Newborns having failed Pulse Oximetry Screening are integrated with Registry. Newborn hearing screening registry provides direct report to SCHS Registry.

Metabolic screening program provides direct report to SCHS Registry. Autism Registry is included in the Registry.

## **Funding**

Funding Source: 90% MCH funds, 10% CDC grant

## Other

Web site: http://www.state.nj.us/health/fhs/sch/schr.shtml

## Contacts

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### New Mexico

New Mexico Birth Defects Prevention And Surveillance System (NM BDPASS)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

Partner: Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators,

Private providers

Program status: Currently collecting data

Start year: 1995

Earliest year of available data: 1995

Organizational location: Department of Health

(Epidemiology/Environment), Department of Health (Maternal and Child

Health)

Population covered annually: 30,000

Statewide: Yes

Current legislation or rule: In January 2000, birth defects became a reportable condition. These conditions are updated by the Office of Epidemiology. This did not involve legislation, only a change in regulations.

Legislation year enacted: January 1, 2000

### Case Definition

Outcomes covered: 740-760.71, Currently focused on major birth defects of interest to Environmental Public Health Tracking.

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective Terminations (All gestational ages)

Age: birth through age 4 years

Residence: Births to New Mexico residents.

## Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Fetal death

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, medical chart review

Pediatric & tertiary care hospitals: Disease index or discharge index, Specialty outpatient clinics, specialty outpatient clinics, including neurosurgery, plastic surgery, pediatric surgical specialists, prenatal diagnostic providers

Third party payers: Medicaid databases, Health maintenance organization (HMOs), Indian health services, Children's Medical Services (CMS)

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.),

Cytogenetic laboratories

Other sources: Physician reports

## Case Ascertainment

Conditions warranting chart review in newborn period: Chart reviews only done to clarify birth defect diagnosis identified through other means, e.g., nonspecific diagnosis such as 749

Coding: CDC coding system based on BPA, ICD-9-CM, ICD10 for deaths

### Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

## Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Stata version 12.0

### Data Analysis

Data analysis software: Stata version 12.0

Quality assurance: Validity checks, Double-checking of assigned codes,

Comparison/verification between multiple data sources

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Grant proposals, Education/public awareness,

Prevention projects

## System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, Link to death file

## **Funding**

Funding Source: 100% CDC Environmental Public Health Tracking grant. We are actively seeking resources to support this effort.

## Other

Web site:

https://nmtracking.unm.edu/health\_effects/birthdefects/about\_birthdefects

## Contacts

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### **New York**

New York State Congenital Malformations Registry (CMR)

**Purpose**: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Community outreach and education

Partner: Universities, Hospitals, Early Childhood Prevention Programs,

March Of Dimes

Program status: Currently collecting data

Start year: 1982

Earliest year of available data: 1983

Organizational location: Department of Health

(Epidemiology/Environment)

Population covered annually: 250,000 - 300,000

Statewide: Yes

Current legislation or rule: Public Health Law Art. 2, Title, II, Sect 225(5)(t) and Art. 2 Title I, sect 206(1)(j): Codes, Rules and

Regulations, Chap 1, State Sanitary Code, part 22.3

Legislation year enacted: 1982

### Case Definition

Outcomes covered: Major malformations - a detailed list is available

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: 2 years

**Residence**: in-state and out-of-state birth to state resident; in-state birth to nonresident; all children born in or residing in New York, up to age 2

### Surveillance Methods

Case ascertainment: Combination of active and passive case

ascertainment, Population based

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Other specialty facilities: Cytogenetic laboratories Other sources: Physician reports, Cytogenetic laboratories

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD9-CM code 740-759

Conditions warranting chart review beyond the newborn period: Any

infant with a codeable defect

Coding: CDC coding system based on BPA, ICD-9-CM

## Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

*Father*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

### **Data Collection Methods and Storage**

Data Collection: Electronic file/report submitted by other agencies

(hospitals, etc.)

Database storage/management: Access, Sybase

### Data Analysis

Data analysis software: SAS, Access, JAVA

**Quality assurance**: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

### **System Integration**

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases

### **Funding**

*Funding Source*: 13.6% General state funds, 10.2% MCH funds, 3.4% Genetic screening revenues, 50.2% CDC grant, 13.3% Other federal funding (non-CDC grants), 9.3% State Superfund

## Other

Web site:

http://www.health.state.ny.us/diseases/congenital\_malformations/cmrhom

Surveillance reports on file: Reports for 1983-2007

## Contacts

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### **North Carolina**

North Carolina Birth Defects Monitoring Program (NCBDMP)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention, Education, Advocacy

Partner: Local Health Departments, Universities, Hospitals,

Environmental Agencies/Organizations, Early Childhood Prevention

Programs, Advocacy Groups, Legislators **Program status**: Currently collecting data

Start year: 1987

Earliest year of available data: 1989

Organizational location: Department of Health (State Center for Health

Statistics)

Population covered annually: 122,000

Statewide: Yes

Current legislation or rule: NCGS 130A-131

Legislation year enacted: 1995

## Case Definition

Outcomes covered: major birth defects

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation

and greater), Elective Terminations (All gestational ages)

Age: up to one year after delivery

Residence: NC resident births, in-state and out-of-state occurrence

## Surveillance Methods

Case ascertainment: Active case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

Third party payers: Medicaid databases

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any birth certificate with a birth defect box checked, All stillborn infants, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: CDC coding system based on BPA

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

### **Data Collection Methods and Storage**

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access, Mainframe, SAS

### Data Analysis

Data analysis software: SAS, Access, Various software for spatial

**Quality assurance**: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, advocacy

## System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, Vital Statistics, Medicaid Paid Claims, MCH Program Data

## Funding

Funding Source: 95% General state funds, 5% CDC grant

## <u>Other</u>

Web site: http://www.schs.state.nc.us/SCHS/bdmp/

## **Contacts**

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### North Dakota

North Dakota Birth Defects Monitoring System (NDBDMS)

Purpose: Surveillance

Partner: Universities, March of Dimes, Department of Human Services

Program status: Currently collecting data

Start year: 2002

Earliest year of available data: 1994

Organizational location: Department of Health (Vital Statistics),
Department of Health (Maternal and Child Health), Department of Health

(Children's Special Health Services) *Population covered annually*: 10,072

Statewide: Yes

Current legislation or rule: North Dakota Century code 23-41

Legislation year enacted: 1941

### Case Definition

Outcomes covered: selected birth defects (NTDs, congenital heart defects, cleft lip and palate, chromosomal anomalies) and other risk factors that may lead to health and developmental problems

Pregnancy outcome: Live Births (All gestational ages and birth weights, Numbers collected and reported via Vital Records), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, numbers collected and reported via Vital Records), Elective Terminations (less than 20 week gestation, 20 weeks gestation and greater, Numbers collected and reported via Vital Records)

Age: Newborn period

Residence: In-state resident births and out of state birth receiving services

in ND

## Surveillance Methods

Case ascertainment: Passive case ascertainment

Vital Records: Birth certificates, Death certificates, Matched birth/death

file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening

program, Cancer registry, AIDS/HIV registry, FAS *Delivery hospitals*: Birth certificate completion

Pediatric & tertiary care hospitals: Specialty outpatient clinics

Third party payers: Medicaid databases

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked

Coding: ICD-9-CM, ICD 10

## **Data Collected**

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity,

Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history *Father*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

### Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other

agencies (hospitals, etc.)

Database storage/management: Access, Mainframe, DB2, SPSS, Excel

### Data Analysis

Data analysis software: SPSS, Access

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

#### System Integration

System links: Link case finding data to final birth file System integration: The program/system/registry is integrated with birth, death, fetal death, Medicaid claims payment, Children with Special Healthcare Needs databases and genetics program data from the Division of Medical Genetics at the University of North Dakota School of Medicine and Health Sciences.

#### Funding

 $\textit{Funding Source} \colon 100\%$  From the State System Development

Initiative(SSDI) Grant

## **Other**

Web site: http://www.ndhealth.gov/cshs/

Surveillance reports on file: North Dakota Birth Defects Monitoring

System -Summary Report 2001-2005

## Contacts

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## Ohio

Ohio Connections For Children With Special Needs (OCCSN)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Local Health Departments, Universities, Hospitals,

Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, NIOSH, Title V CSHCN, Ohio

Hospital Association

Program status: Currently collecting data

Start year: 2006

Earliest year of available data: 2008

Organizational location: Department of Health (Maternal and Child

Health)

Population covered annually: 143,000

Statewide: Yes

Current legislation or rule: Ohio Revised Code (ORC) 3705.30 - 3705.36, signed into law in July, 2000.

"The Director of Health shall establish and, if funds for this purpose are available, implement a statewide birth defects information system for the collection of information concerning congenital anomalies, stillbirths, and abnormal conditions of newborns." Ohio Administrative Code (OAC)

3701-57-01 to 3701-57-04.revised 2010

Legislation year enacted: 2000

#### Case Definition

*Outcomes covered*: Major birth defects recommended by NBDPN, disorders on state newborn bloodspot panel, disorders related to infant hearing loss

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Up to 5 years of age

**Residence**: Ohio children 0 to 5 years of age seen for medical care at a hospital in Ohio; all in and out of state births and fetal deaths to state residents

## Surveillance Methods

*Case ascertainment*: Passive case ascertainment, and passive case ascertainment with follow-up for certain disorders.

*Vital Records*: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates (20 weeks gestation and greater)

Other state based registries: Programs for children with special needs, Newborn metabolic screening program, Title V CSHCN Program data, Genetics Program Data System, Part C Early Intervention System Data, Newborn Bloodspot Screening Data

**Delivery hospitals**: Hospital data for medical records and billing **Pediatric & tertiary care hospitals**: Hospital data for medical records and billing

Other specialty facilities: Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any birth certificate with a birth defect box checked, ICD-9-CM, ICD-10 (death certificates), or named congenital anomaly

Coding: ICD-9-CM

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

 ${\it Mother}$ : Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

Father: Identification information (name, address, date-of-birth, etc.)

#### Data Collection Methods and Storage

Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.), Reporting hospitals upload CSV flat file to secure website for integration. Low volume reporters can manually key data into user interface on secure internet site.

**Database storage/management:** SQL 2008 server. External system data methods and storage: ODBC connection with SAS. SAS import of other data sets and merge export of cohort line lists to MS Excel (follow-up)

### Data Analysis

Data analysis software: SAS, MS Excel, FRIL

Quality assurance: Validity checks, Comparison/verification between

multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Observed vs. expected analyses, Epidemiologic studies (using only program data), Referral, Grant proposals, Education/public awareness, Prevention projects, IRB approved research projects

## **System Integration**

System links: Link to other state registries/databases

System integration: OCCSN data system shares common demographic

file with Vital Statistics and Genetics Program data system

## **Funding**

Funding Source: 100% CDC grant

## <u>Other</u>

Web site:

http://www.odh.ohio.gov/odhPrograms/cmh/bdefects/birthdefects1.aspx

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### Oklahoma

Oklahoma Birth Defects Registry (OBDR)

Purpose: Surveillance, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators,

Cytogenetics/ & Medical Genetics *Program status*: Currently collecting data *Start year*: 1992; statewide 1994

Earliest year of available data: 1992; 1994 statewide

Organizational location: Department of Health (Prevention and

Preparedness)

Population covered annually: 55,000

Statewide: Yes

Current legislation or rule: 63 O.S. Section 1-550.2

Legislation year enacted: 1992

## Case Definition

*Outcomes covered*: modified 6-digit ICD-9-CM codes for birth defects and genetic diseases (CDC/BPA)

 $\label{eq:pregnancy outcome} \textit{Pregnancy outcome} : \text{Live Births } (\geq 20 \text{ weeks gestation}), \text{ Fetal deaths - stillbirths, spontaneous abortions, etc. } (20 \text{ weeks gestation and greater}),$ 

Elective Terminations (20 weeks gestation and greater)

Age: 2 years

Residence: in-state births to state residents

### Surveillance Methods

Case ascertainment: Active case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Fetal death

Other state based registries: Newborn hearing screening program,

Newborn metabolic screening program

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics

*Pediatric & tertiary care hospitals*: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics

Third party payers: Indian health services, military hospitals delivering babies

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code

Conditions warranting chart review beyond the newborn period: Any

infant with a codeable defect

Coding: CDC coding system based on BPA

#### Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

## **Data Collection Methods and Storage**

Data Collection: Printed abstract/report filled out by staff

Database storage/management: Access

#### Data Analysis

Data analysis software: SAS, Access, ArcView GIS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Timeliness, editing of all completed abstracts Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, program quality assurance

## **Funding**

Funding Source: 13% General state funds, 57% MC funds, 30% CDC grant

## Other

Web site:

http://www.ok.gov/health/Child\_and\_Family\_Health/Screening,\_and\_Special\_Services/

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### Oregon

Data Collected

Data Analysis

System Integration

Birth Anomalies Registry (BAR)

Purpose: Surveillance

Partner: Environmental Agencies/Organizations, Advocacy Groups,

Legislators

Program status: Currently collecting data

Start year: 2013

Earliest year of available data: None yet ready for publication Organizational location: Public Health Division (Maternal and Child

Health)

Population covered annually: 45,000

Statewide: Yes

Current legislation or rule: None

Case Definition

Outcomes covered: EPHT-12

**Pregnancy outcome**: Live Births (All gestational ages and birth weights)

Age: 0-1 years now

Residence: In-state births to state residents

Surveillance Methods

Case ascertainment: Link birth certificate to hospital discharge dataset

Vital Records: Birth certificates

Delivery hospitals: Hospital Discharge Dataset

Pediatric & tertiary care hospitals: Hospital Discharge Dataset

Third party payers: Medicaid data

Case Ascertainment

Conditions warranting chart review in newborn period: None at this point; undecided regarding future expanded list of anomalies Coding: CDC coding system based on BPA, ICD-9-CM

in a party payers. Friedlead

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<u>Contacts</u> Suzanne Zane, DVM

Funding

Maternal & Child Health Epidemiologist Birth Anomalies Registry, Maternal and Child Health Section

**Center for Prevention and Health Promotion** 

System links: Link to other state databases

from Maternal and Child Health Bureau.

Infant/fetus: Birth defect diagnostic information

Demographic information (race/ethnicity, sex, etc.)

Illnesses/conditions, Prenatal care

Data analysis software: SPSS

Mother: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.), Gravidity/parity,

Father: Identification information (name, address, date-of-birth, etc.),

Data use and analysis: Routine statistical monitoring at this point

Funding Source: Environmental Public Health Tracking (EPHT), Title V

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## Pennsylvania

Pennsylvania Birth Defects Surveillance Database

Program status: No surveillance program

Organizational location: Department of Health (Vital Statistics),

Department of Health (Maternal and Child Health)

**Population covered annually**: 142,370 total live births in 2001; 142,388 total live births in 2002; 145,952 total live births in 2003; 144,499 total

live births in 2004. *Statewide*: Yes

**Data Collected** 

Mother: Maternal risk factors

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### Puerto Rico

Puerto Rico Birth Defects Surveillance and Prevention System (PRBDSS)

Purpose: Surveillance, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy

Groups

Program status: Currently collecting data

Start year: 1995

Earliest year of available data: 1995

Organizational location: Department of Health (Maternal and Child

Health)

Population covered annually: 42,000

Statewide: Yes

Current legislation or rule: Yes, Law 351 Legislation year enacted: September 16th, 2004

## Case Definition

*Outcomes covered*: Selected birth defects - neural tube defects, cleft lip and/or cleft palate, talipes equinovarus, limb defects, ventral wall defects, ambiguous genitalia, trisomy 13, 18 and 21, albinism, congenital heart defects, hipos/epispadias, Jarcho-Levin syndrome, anotia, microtia, anophthalmia, microphthalmia and bladder extrophy.

*Pregnancy outcome*: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective Terminations (All gestational ages)

Age: up to 6 years after delivery

Residence: in-state birth to state residents

### Surveillance Methods

Case ascertainment: Active case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs

*Third party payers*: Medicaid databases, Health maintenance organization (HMOs)

 ${\it Other specialty facilities:} \ {\it Prenatal diagnostic facilities (ultrasound, etc.)},$ 

Cytogenetic laboratories

Other sources: Physician reports

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All elective abortions, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular

condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codeable defect

Coding: ICD-9-CM

#### Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Birth defect diagnostic information

**Mother**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity,

Prenatal diagnostic information

Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

## Data Collection Methods and Storage

**Data Collection**: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access

### Data Analysis

Data analysis software: SPSS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

## **Funding**

Funding Source: 70% MCH funds, 30% CDC grant

## Other

Web site: http://www.salud.gov.pr

Surveillance reports on file: PR Birth Defects Datebook 2012

## **Contacts**

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### **Rhode Island**

Rhode Island Birth Defects Program

Purpose: Surveillance, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention

Programs, Advocacy Groups, families *Program status*: Currently collecting data

Start year: 2000

Earliest year of available data: 2002

Organizational location: Department of Health (Center for Health Data

and Analysis)

Population covered annually: 11,000

Statewide: Yes

Current legislation or rule: Title 23, Chapter 13.3 of Rhode Island General Laws requires the development of a birth defects surveillance, reporting and information system that will: a) describe the occurrence of birth defects in children up to age five; b) detect trends of morbidity and mortality; and c) identify newborns and children with birth defects to intervene on a timely basis for treatment.

Legislation year enacted: 2003

### Case Definition

Outcomes covered: All birth defects and genetic diseases

*Pregnancy outcome*: Live Births (All gestational ages and birth weights, Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective Terminations (20 weeks gestation and greater)

Age: Birth-4 years Residence: RI residents

## Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment

Vital Records: Birth and death certificates, Matched birth/death file Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, RI has an integrated child health information system called KIDSNET, which links data from 9 programs including: Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning;

WIC; Home Visiting and Vital Records *Delivery hospitals*: Discharge summaries

Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities,

Maternal serum screening facilities *Other sources*: Physician reports

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759 and 760.71, Any chart with a selected list of ICD9-CM codes outside 740-759, All stillborn infants, All elective abortions, All prenatal diagnosed or suspected cases, Chart reviews are conducted for infants born at the regional perinatal center and the 6 other maternity hospitals who were identified with an ICD-9 code 740-759 and other sentinel conditions

Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: ICD-9-CM

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

## Data Collection Methods and Storage

**Data Collection:** Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access, Oracle

## Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

## **System Integration**

System links: Link to other state registries/databases, Link to KIDSNET (Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting; and Vital Records); hospital discharge database

System integration: Integrated into KIDSNET for web-based provider reporting

## **Funding**

Funding Source: 10% MCH funds, 85% CDC grant, 5% State

## **Other**

Web site: http://www.health.ri.gov/programs/birthdefects Surveillance reports on file: 2012 Rhode Island Birth Defects Data Book Comments: Chart reviews are also conducted for ICD-9-CM codes 740-759 and other sentinel conditions after the newborn period from sources such as, genetics counseling and testing centers.

## Contacts

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### **South Carolina**

South Carolina Birth Defects Program (SCBDP)

 ${\it Purpose} \hbox{: Surveillance, Research, Referral to Prevention/Intervention}$ 

Partner: Local Health Departments, Universities, Hospitals,

 $Environmental\ Agencies/Organizations,\ Advocacy\ Groups,\ Greenwood$ 

Genetic Center (GGC)

Program status: Currently collecting data

Start year: GGC began monitoring in 1992; transitioned to SC DHEC and

expanded in 2006

Earliest year of available data: via GGC, for 3 categories of defects,

since 1993

Organizational location: Department of Health (Maternal and Child

Health)

Population covered annually: 57,338

Statewide: Yes

Current legislation or rule: A281,R308,H4115

Legislation year enacted: 2004

Case Definition

Outcomes covered: Neural tube defects, cardiovascular defects, genitourinary defects, musculoskeletal defects, orofacial clefts

Pregnancy outcome: Live Births (All gestational ages and birth weights),

 $Fetal\ deaths\ \hbox{-}\ still births,\ spontaneous\ abortions,\ etc.\ (All\ gestational$ 

ages), Elective Terminations (All gestational ages)

Age: Up to two years of age

Residence: Currently monitoring in-state births to persons residing in

South Carolina

Surveillance Methods

Case ascertainment: Active case ascertainment

Vital Records: Birth certificates, Death certificates, Matched birth/death

file, Fetal death certificates, Elective termination certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening

program, Cancer registry, autopsy

Delivery hospitals: Disease index or discharge index, Discharge

summaries, Postmortem/pathology logs, ICD-9 codes

Pediatric & tertiary care hospitals: Disease index or discharge index,

Discharge summaries, ICD-9 codes

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease, All stillborn infants, All elective abortions, All prenatal diagnosed or suspected cases, birth certificate with neural tube defect box checked

Conditions warranting chart review beyond the newborn period: Any

infant with a codeable defect

Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures,

Infant complications, Birth defect diagnostic information

**Mother**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information,

Pregnancy/delivery complications

Data Collection Methods and Storage

**Data Collection**: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database storage/management: Access, SQL Server

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Doublechecking of assigned codes, Comparison/verification between multiple

data sources, Clinical review

*Data use and analysis*: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data),

Needs assessment, Referral, Grant proposals, Education/public

awareness, Prevention projects

**System Integration** 

System links: Link case finding data to final birth file, Link to

environmental databases, SC Vital Records *System integration*: SC Vital Records

**Funding** 

Funding Source: 100% General state funds

Other

Web site: http://www.scdhec.gov/health/mch/rpu/bd.htm

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South Dakota

**Program status**: No surveillance program

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### Tennessee

Tennessee Birth Defects Registry (TBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Early

Childhood Prevention Programs, Legislators *Program status*: Currently collecting data

Start year: 2000

Earliest year of available data: 1999

Organizational location: Department of Health; Office of Policy,

Planning & Assessment: Research Division *Population covered annually*: 85,000

Statewide: Yes

Current legislation or rule: TCA 68-5-506

Legislation year enacted: 2000

## Case Definition

Outcomes covered: 45 major structural birth defects

*Pregnancy outcome*: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (500 grams or more, or in the absence of weight, 22 completed weeks of gestation or more)

Age: up to one year after delivery

Residence: in and out of state births to state residents

## Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based,

Hospital based

Vital Records: Birth certificates, Death certificates, Matched birth/death

file, Fetal death certificates

Other state based registries: Newborn metabolic screening program,

Hospital Discharge Data System

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Midwifery facilities: Midwifery facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease, All stillborn infants, ICD-9-CM code 760.71 Conditions warranting chart review beyond the newborn period: Any

infant with a codeable defect

Coding: ICD-9-CM

### Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information,

Pregnancy/delivery complications, Maternal risk factors

Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

### Data Collection Methods and Storage

**Data Collection**: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

agencies (nospitais, etc.)

Database storage/management: Access, SQL Server

## Data Analysis

Data analysis software: SAS, Access, Arc-GIS

*Quality assurance*: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Education/public awareness, Prevention projects

## **System Integration**

System links: Link to other state registries/databases, Link case finding data to final birth file

## **Funding**

Funding Source: 100% general state funds

## Other

Web site: http://hit.state.tn.us/Reports.aspx

Surveillance reports on file: Tennessee Birth Defects Registry 2003-

2008

## **Contacts**

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### Texas

Texas Birth Defects Epidemiology And Surveillance Branch (TBDES)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

Partner: Universities, Hospitals, Environmental Agencies/Organizations,

Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1994

Earliest year of available data: 1996

Organizational location: Department of Health

(Epidemiology/Environment)

Population covered annually: 385,746 in 2010

Statewide: Yes

Current legislation or rule: Health and Safety Code, Title 2, Subtitle D,

Section 1, Chapter 87.

Legislation year enacted: 1993

## Case Definition

Outcomes covered: all major structural birth defects and fetal alcohol syndrome

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective Terminations (All gestational ages)

Age: up to one year after delivery - FAS up to 6 years Residence: in and out of state births to state residents

### Surveillance Methods

Case ascertainment: Active case ascertainment, Population based Vital Records: We are now using fetal death certificates (2009+) to aid in case finding

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, genetics logs, stillbirth logs, radiology logs

*Pediatric & tertiary care hospitals*: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics, genetics logs, radiology logs

**Midwifery facilities**: Midwifery facilities **Other sources**: licensed birthing centers

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Infants with low birth weight or low gestation (<34 weeks GA), All stillborn infants Conditions warranting chart review beyond the newborn period: CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), GU condition (e.g., recurrent infections), Cardiovascular condition, Any infant with a codeable defect

Coding: CDC coding system based on BPA

## Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

### Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff

Database storage/management: Oracle

## Data Analysis

Data analysis software: SAS, Access

*Quality assurance*: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Clinical review, Timeliness, re-casefinding,

re-review of medical records

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects

### System Integration

System links: Link to other state registries/databases, Link to environmental databases, link registry to vital records for demographic data, special projects linking to other files (Texas Health Data for geocodes, Newborn Screening data)

#### **Funding**

Funding Source: 48% General state funds, 52% MCH funds \* Note: does not include CDC-funded Texas Birth Defects Research Center funds

## Other

Web site: www.dshs.state.tx.us/birthdefects/

Comments: In order to maintain efficiency with increasing workloads; we stopped the routine review and abstraction of mother's medical records (we still occasionally abstract specific information from the mother's record when it's needed and can't be found elsewhere) and that change only applies to live born cases (we still routinely review and abstract information from mother's medical records for other pregnancy outcomes).

## Contacts

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## Utah

Utah Birth Defect Network (UBDN)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention, education

Partner: Universities, Hospitals, Environmental Agencies/Organizations,

Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1994

Earliest year of available data: 1994

Organizational location: Department of Health (Maternal and Child

Health), CSHCN, University *Population covered annually*: 50,000

Statewide: Yes

Current legislation or rule: Birth Defect Rule (R398-5)

Legislation year enacted: 1999

Case Definition

Outcomes covered: 742.000 - 759.000

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, stillbirths 20 weeks gestation or greater), Elective

Terminations (All gestational ages)

Age: 2 years

Residence: maternal residence in Utah at time of delivery

## Surveillance Methods

Case ascertainment: Combination of active and passive case

ascertainment, Population based

Vital Records: Birth certificates, Death certificates, Fetal death

certificates

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, Champions report live births delivered at their respective hospitals

*Pediatric & tertiary care hospitals*: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

Midwifery facilities: Midwifery facilities

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Other sources: Physician reports, lay midwives

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, all fetal deaths certificates, NICU reports, infant deaths are reviewed

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Any infant with a codeable defect

Coding: CDC coding system based on BPA

### Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

# Data Collection Methods and Storage

Data Collection: Electronic abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic

file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access

#### Data Analysis

Data analysis software: SPSS, SAS, Access, Epi2000, Stata 8
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness, logical checks, duplicate check in tracking and surveillance module, case record form checked for completeness, timeliness through system, manual review of subset of surveillance module case data compared to case record form.

Data use and analysis: Routine statistical monitoring, Public health

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects, Oral Facial Cleft Case-Control Study, UT Center for Birth Defects Research and Prevention

## **System Integration**

System links: Link to environmental databases, link to birth records

**Funding** 

Funding Source: 100%MCH funds

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### Vermont

Birth Information Network (BIN)

**Purpose**: Surveillance, Referral to Services, Referral to Prevention/Intervention, Prevention education

**Partner**: Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Green Mountain

Care Board

Program status: Currently collecting data

Start year: 2006

Earliest year of available data: 2006

Organizational location: Department of Health (Statistics)

Population covered annually: 6,200

Statewide: Yes

Current legislation or rule: Act 32 (TITLE 18 VSA §5087)

Legislation year enacted: 2003

Case Definition

Outcomes covered: Major birth defects and genetic diseases, very low

birth weight (less than 1500 grams)

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: up to one year after delivery

Residence: in and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Matched birth/death

file

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening

program

**Delivery hospitals**: Discharge summaries, Specialty outpatient clinics **Pediatric & tertiary care hospitals**: Discharge summaries, Specialty outpatient clinics

Third party payers: Medicaid databases, Multi-payer claims database

*Other specialty facilities*: Cytogenetic laboratories *Other sources*: Physician reports, Autopsy Reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked

Conditions warranting chart review beyond the newborn period: Any

infant with a codeable defect

Coding: ICD-9-CM

**Data Collected** 

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity,

Illnesses/conditions, Prenatal care, Maternal risk factors

Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

**Data Collection**: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies

(hospitals, etc.)

Database storage/management: Access

Data Analysis

Data analysis software: SPSS, Access, Excel

Quality assurance: Comparison/verification between multiple data

sources, Data/hospital audits, Clinical review, Timeliness

*Data use and analysis*: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Observed vs expected analyses, Referral, Grant proposals, Education/public

awareness, Prevention projects

**System Integration** 

System links: Link to other state registries/databases, Link case finding

data to final birth file, Link to environmental databases

**Funding** 

Funding Source: 100% CDC grant

Other

Web site: http://healthvermont.gov/tracking/health\_birthdefects.aspx

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## Virginia

Virginia Congenital Anomalies Reporting And Education System (VACARES)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Universities, Hospitals, Early Childhood Prevention Programs, Children with Special Health Care Needs, Care Connection for Children

Network

Program status: Currently collecting data

Start year: 1985

Earliest year of available data: 1987

Organizational location: Department of Health (Vital Statistics),
Department of Health: Division of Child and Family Health, Child Health

Programs, Genetics and Newborn Screening *Population covered annually*: ~102,000

Statewide: Yes

Current legislation or rule: Health Law 32.1-69.1,-69.1:1,-69.2 Legislation year enacted: 1985, amended 1986, 1988, 2006

### Case Definition

Outcomes covered: Major birth defects and genetic diseases

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages,

Only for the Neural tube defect and Trisomy cases requested)

Age: Below 24 months of age

Residence: All in state births; Out of state births hospitalized in state up

to 24 months of age with reportable birth defect

### Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Matched birth/death file

Other state based registries: Newborn hearing screening program,

Newborn metabolic screening program

Delivery hospitals: Discharge summaries, medical records abstracts codes

from charts

Pediatric & tertiary care hospitals: Discharge summaries

Other specialty facilities: Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease),, Any birth certificate with a birth defect box checked, All neonatal deaths, Chart review done by the coders in Health Information Management

Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: ICD-9-CM, ICD-10 for death certificate

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

*Father*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

### **Data Collection Methods and Storage**

**Data Collection**: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Oracle

### Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

### **System Integration**

System links: Link to other state registries/databases

System integration: Virginia birth defects registry data (VaCARES) are reported by hospitals to the state health department via the Virginia Infant Screening and Infant Tracking System (VISITS II), which is a Web-based integrated data tracking and management system. VISITS II is a component of the Virginia Vital Events and Screening Tracking System (VVESTS), which also includes the Virginia electronic birth certificate and Virginia Early Hearing Detection and Intervention Program databases.

## **Other**

Web site: http://www.vahealth.org/gns/vaCares.htm

Surveillance reports on file: Virginia Congenital Anomalies Reporting and Education System: Birth Defect Surveillance Data 1989-1998 available on Web site.

Additional information on file: Family Brochure and Parent Fact Sheets (English and Spanish) available on Web site.

## **Contacts**

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## Virginia

Virginia Congenital Anomalies Reporting And Education System (VACARES)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

**Partner**: Universities, Hospitals, Early Childhood Prevention Programs, Children with Special Health Care Needs, Care Connection for Children

Network

Program status: Currently collecting data

Start year: 1985

Earliest year of available data: 1987

Organizational location: Department of Health (Vital Statistics), Department of Health (Other, please specify):, Division of Child and Family Health, Child Health Programs, Genetics and Newborn Screening

Population covered annually: ~102,000

Statewide: Yes

Current legislation or rule: Health Law 32.1-69.1,-69.1:1,-69.2 Legislation year enacted: 1985, amended 1986, 1988, 2006

### Case Definition

Outcomes covered: Major birth defects and genetic diseases

*Pregnancy outcome*: Live Births, All gestational ages and birth weights, Fetal deaths (stillbirths, spontaneous abortions, etc.), All gestational ages, Only for the Neural tube defect and Trisomy cases requested

Age: Below 24 months of age

Residence: All in state births; Out of state births hospitalized in state up

to 24 months of age with reportable birth defect

### Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Matched birth/death file

Other state based registries: Newborn hearing screening program,

Newborn metabolic screening program

Delivery hospitals: Discharge summaries, medical records abstracts codes

from charts

Pediatric & tertiary care hospitals: Discharge summaries

Other specialty facilities: Genetic counseling/clinical genetics facilities

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, All neonatal deaths, Chart review done by the coders in Health Information Management

Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: ICD-9-CM, ICD-10 for death certificate

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

## **Data Collection Methods and Storage**

**Data Collection**: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies

(hospitals, etc.)

Database storage/management: Oracle

### Data Analysis

Data analysis software: SAS, Access

*Quality assurance*: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness *Data use and analysis*: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

### **System Integration**

System links: Link to other state registries/databases

System integration: Virginia birth defects registry data (VaCARES) are reported by hospitals to the state health department via the Virginia Infant Screening and Infant Tracking System (VISITS II), which is a Web-based integrated data tracking and management system. VISITS II is a component of the Virginia Vital Events and Screening Tracking System (VVESTS), which also includes the Virginia electronic birth certificate and Virginia Early Hearing Detection and Intervention Program databases.

## Funding

Funding Source: 100% MCH funds

## **Other**

Web site: http://www.vahealth.org/gns/vaCares.htm

Surveillance reports on file: Virginia Congenital Anomalies Reporting and Education System: Birth Defect Surveillance Data 1989-1998 available on Web site.

Additional information on file: Family Brochure and Parent Fact Sheets (English and Spanish) available on Web site.

## Contacts

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### Washington

Washington State Birth Defects Surveillance System (BDSS)

Purpose: Surveillance

Partner: Local Health Departments, Universities, Hospitals,

Environmental Agencies/Organizations *Program status*: Currently collecting data *Start year*: 1986- Active and 1991- Passive *Earliest year of available data*: 1987

Organizational location: Department of Health (Office of Healthy

Communities)

Population covered annually: 90,000

Statewide: Yes

Current legislation or rule: Notifiable Conditions: WAC 246-101

Legislation year enacted: 2000

### Case Definition

Outcomes covered: From 1987 to 1991 (active surveillance), and from 1991 to the 2000 (passive surveillance), the cases reportable to the Birth Defects Registry included those with ICD-9-CM codes 740-759, selected primary cancers, selected metabolic conditions, and FAS/FAE. Since the adoption of the Notifiable Conditions law in 2000, conditions subject to mandatory reporting are neural tube defects, orofacial clefts, limb deficiencies, abdominal wall defects, hypospadias/epispadias and Down Syndrome. FAS/FAE, Cerebral Palsy and Autism are designated as reportable with systems being established to ascertain cases outside the hospital setting.

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

*Age*: We ascertain cases through 1 year of age for structural defects and to age ten for FAS/FAE, Cerebral Palsy and Autism.

Residence: resident births; children born, diagnosed or treated in-state

## Surveillance Methods

Case ascertainment: Passive case ascertainment Vital Records: Birth certificates, Fetal death certificates

Other state based registries: Programs for children with special needs

Delivery hospitals: Disease index or discharge index

Pediatric & tertiary care hospitals: Disease index or discharge index Other sources: university-based FAS/FAE and Autism specialty centers

## Case Ascertainment

*Coding*: ICD-9-CM, ICD-9-CM, FAS/FAE coding scheme will be utilized in data collection and case description for FAS/FAE cases

### Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Tests and procedures, Birth defect diagnostic information

**Mother**: Identification information (name, address, date-of-birth, etc.) **Father**: Identification information (name, address, date-of-birth, etc.)

### **Data Collection Methods and Storage**

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Casefinding Log listing of all data elements required for each case are completed by Medical Records staff, sometimes in conjunction with hospital Information Systems staff. Several facilities submit print-outs from data query of internal system of discharge data. Minimal use of diskette or other forms of electronic data transfer. A webbased reporting system is currently in development.

Database storage/management: Web-based SQL server

#### Data Analysis

Data analysis software: SAS, Stata

Quality assurance: Validity checks, Comparison/verification between

multiple data sources

Data use and analysis: Routine statistical monitoring, Baseline rates, Monitoring outbreaks and cluster investigation, Time trends, Observed

vs. expected analyses, Education/public awareness

### **System Integration**

System links: Link case finding data to final birth file, CSHCN program participant file

## **Funding**

Funding Source: 30% General state funds, 70% MCH funds

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## West Virginia

West Virginia Birth Defects Surveillance System Congenital Abnormalities Registry, Education And Surveillance System (CARESS)

Purpose: Surveillance, Research, Referral to Services, Referral to

Prevention/Intervention

Partner: Universities, Hospitals, Early Childhood Prevention Programs,

Advocacy Groups

Program status: Currently collecting data

Start year: 1989

Earliest year of available data: 1989

Organizational location: Department of Health

(Epidemiology/Environment), Department of Health (Vital Statistics),

Department of Health (Maternal and Child Health)

Population covered annually: 21,000

Statewide: Yes

Current legislation or rule: State Statute Section 16-5-12a Legislation year enacted: 1991Legislation updated: 2002

## Case Definition

Outcomes covered: congenital anomalies of ICD-9 codes 740-759, 760, 764, 765, 766

**Pregnancy outcome**: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective Terminations (20 weeks gestation and greater) **Age:** 0.6 years

Residence: in and out of state births to state residents

## Surveillance Methods

*Case ascertainment*: Passive case ascertainment, monthly reports sent from birthing facilities across the state and reproductive outcome forms submitted by facilities and individual physicians

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Elective termination certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance, Cancer registry, AIDS/HIV registry, SIDS/SUID

*Delivery hospitals*: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics, physicians complete reproductive outcomes forms for those diagnosed after delivery

Other specialty facilities: Genetic counseling/clinical genetics facilities Other sources: Physician reports, pediatric referrals of children diagnosed after delivery and discharge

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation (less than 2500 grams or less than 37 weeks), All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, All infants in NICU or special care nursery

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), GU condition (e.g., recurrent infections), Cardiovascular condition, All infant

deaths (excluding prematurity), Childhood deaths between 1 and 6, Ocular conditions, Auditory/hearing conditions, Any infant with a codeable defect

Coding: ICD-9-CM, ICD-10-CM

#### Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

### **Data Collection Methods and Storage**

**Data Collection**: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access

### Data Analysis

Data analysis software: Access

**Quality assurance**: Validity checks, Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

## **System Integration**

*System links*: Link to other state registries/databases, Link case finding data to final birth file, Plans continue to link several programs housed in the Office of Maternal, Child and Family Health.

## <u>Funding</u>

Funding Source: 100% MCH Title V Block Grant funds

## **Other**

Web site: http://www.wvdhhr.org/caress/

## Contacts

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### Wisconsin

Wisconsin Birth Defects Registry (WBDR)

Purpose: Surveillance, Research, Referral to Services
Partner: Local Health Departments, Universities, Hospitals,

Environmental Agencies/Organizations, Early Childhood Prevention

Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 2004

Earliest year of available data: 2004

Organizational location: Department of Health (Maternal and Child

Health)

Population covered annually: ~69,000

Statewide: Yes

Current legislation or rule: Wisconsin Statutes 253.12

Rules: HFS 116--Took effect April 1, 2003 Legislation year enacted: 2000; rules 2003

Case Definition

Outcomes covered: structural malformations, deformations, disruptions,

or dysplasias; genetic, inherited, or biochemical diseases.

*Pregnancy outcome*: Live Births (20 weeks gestational age or greater), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation

and greater)

Age: birth to 2 years

Residence: Statute mandates reporting of birth defects diagnosed or

treated in Wisconsin regardless of residence status

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based

Delivery hospitals: case reports from nursery managers

Pediatric & tertiary care hospitals: case reports from pediatric specialty

clinics

Midwifery facilities: Midwifery facilities

Third party payers: Health maintenance organization (HMOs)

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

Coding: Wisconsin codes assigned to a specific list of birth defects cross-

walked to ICD-9-CM where possible

Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic

information

 ${\it Mother}$ : Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

Father: Identification information (name, address, date-of-birth, etc.),

Demographic information (race/ethnicity, sex, etc.)

**Data Collection Methods and Storage** 

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Organizations can report by uploading multiple records from their electronic patient records system to the WBDR secure website.

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Comparison/verification between

multiple data sources

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness,

Prevention projects

**System Integration** 

System links: Legislation currently prohibits data linkage.

**Funding** 

Funding Source: MCH Block grant - staffing and Birth Record/Certificate fees - Registry/Program Private foundation

Other

Web site: https://phin.wisconsin.gov/wbdr/index.html

 ${\it Surveillance\ reports\ on\ file:}$ 

http://www.dhs.wisconsin.gov/health/children/birthdefects/index.htm

Comments: We have stopped printing reports as of 2008 and instead post

them to our website.

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Wyoming

**Program status**: Interested in developing a surveillance program

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## **US Department of Defense**

United States Department of Defense (DoD) Birth and Infant Health Registry

Purpose: Surveillance, Research

Partner: Universities, Hospitals, Other DoD Programs

Program status: Currently collecting data

Start year: 1998

Earliest year of available data: 1998

Organizational location: Deployment Health Research Department, Naval

Health Research Center, San Diego, CA

Population covered annually: approximately 100,000 per year Statewide: No, National/Worldwide; includes all DoD beneficiaries Current legislation or rule: Assistant Secretary of Defense, Health Affairs

Policy Memorandum

Legislation year enacted: 1998

## Case Definition

*Outcomes covered*: Outcomes include those birth defects listed in the case definition of the National Birth Defects Prevention Network. For a birth defect to be represented, the diagnosis must appear at least once in an inpatient record, or at least twice on two separate dates for outpatient encounters. Same sex multiples are excluded from analysis.

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: birth to 1 year

Residence: Worldwide; any birth to a US military beneficiary.

### Surveillance Methods

*Case ascertainment*: Combination of active and passive case ascertainment, Population based, electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries.

**Delivery hospitals**: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data.

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data.

Third party payers: All inpatient and outpatient encounters are captured in standardized DoD data.

*Other sources*: Validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from military facilities.

## Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from military healthcare facilities.

Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: ICD-9-CM

## Data Collected

*Infant/fetus*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

*Mother*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications

*Father*: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions

### **Data Collection Methods and Storage**

Data Collection: Electronic file/report submitted by other agencies

(hospitals, etc.)

Database storage/management: Access, SAS

#### Data Analysis

Data analysis software: SAS

**Quality assurance**: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Prevention projects

### **System Integration**

System links: DoD databases
System integration: DoD databases

#### **Funding**

Funding Source: 100% other federal funding (non-CDC grants)

#### Other

Web site: http://www.med.navy.mil/sites/nhrc/Pages/Department164.aspx Surveillance reports on file: DoD/Health Affairs policy memorandum; annual reports

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